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ABSTRACT

Presented are 10 papers resulting from a workshop, involving representatives from 33 state developmental disabilities councils, designed to examine common problems and issues confronting developmentally disabled citizens in rural areas. Entries include the following titles and authors: "Who, What, and Where--Studying Prevalence of Developmental Disabilities in West Virginia" (D. Lindberg); "Service Delivery in Rural Areas--Context, Problems, and Issues" (C. Horejsi); "Kittens Versus Cats" (some strategies for developing effective rural programs, with emphasis on problems specific to developmental programs for adults) by R. Harper and R. Schalock; "Developmental Disabilities Manpower Development in Rural Areas--County Agent's Model" (F. Dennis); "Southwestern New Mexico Services to Handicapped Children and Adults, Inc.--A Rural Delivery System" (B. Gray); "Client Identification--Idaho Child Find and Public Awareness" (L. Gibbs); "TRIP--A Comprehensive Transportation Plan for West Virginia" (R. Payson); "Hi-Line Training--An Approach to Home Training and Respite Care for the Developmentally Disabled in Rural Montana" (S. Hubbard); "Service to the Developmentally Disabled--A Component of a Model Rural Health System" (S. Davis); and "Seeds of Common Sense" (description of a program designed to maximize resources available in semi-rural Connecticut) (T. Bergeron). Provided in the appendixes are reports from special workshop sessions on the concerns of minimum allotment states and minority populations in rural areas. (SBH)

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RURAL SERVICES

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Editors

This document was developed following a Rural Services Workshop sponsored jointly by the National Conference on Developmental Disabilities (NCDD) and the Developmental Disabilities Technical Assistance System (DD/TAS) in San Francisco, California, September 16-18, 1976.

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INTRODUCTION

Approximately one third of this country's population lives in rural areas, defined as outside metropolitan areas of 50,000 population. Providing services to the developmentally disabled in these areas often requires a different approach than would be appropriate in urban or sub-urban areas.

By definition, rural areas have a low population density. Because people live further apart, more transportation is obviously necessary to bring the rural developmentally disabled into contact with the services they need. Besides obvious differences in transportation needs, there are other differences in the characteristics of rural areas and rural populations that imply differences in how the developmentally disabled are best served.

In 1975 the National Conference on Developmental Disabilities recognized that delivery of services to the developmentally disabled in rural areas is a matter deserving special attention by appointing a rural services committee. This committee was composed of:

Alice Angney, Chairperson; Vermont DD Council Chairperson.
Susan Hubbard; Montana DD Council Staff Director.
Thomas E. Scheinost; South Dakota Staff Director.
Allan Ziegler; Washington DD Council Staff Director.
George Bennett; West Virginia DD Council Staff Director.

After several preliminary sessions, a meeting of the committee, plus representatives from Developmental Disabilities Technical Assistance System (DD/TAS) and several Regional DD Offices, was held to identify a workscope for the year. At this meeting, on February 2, 1976, several activities were planned.

One of the planned activities was to be a workshop for the DD Councils, aimed at presenting information on exemplary rural service delivery activities. It was suggested that the workshop both illustrate specific strategies for service delivery and allow participating states to share information on their own exemplary programs. DD/TAS was asked to design the workshop and to publish a proceedings document.

Shortly after this meeting the committee decided to hold the rural services workshop in San Francisco on September 16, 17, and 18, just prior to a scheduled meeting of National Conference on Developmental Disabilities (NCDD).

Planning for the workshop began with a survey of all state DD Councils to determine (1) which states were interested in participating in the workshop, and (2) what concerns regarding rural services the Councils wished to have addressed at the conference. Twenty-six states responded that they would like to attend and the concerns most nominated for inclusion were: transportation, resource acquisition, and development of service delivery systems specifically for rural areas.

Based on this survey, the NCDD Rural Services Committee, with technical assistance from DD/TAS, planned the workshop agenda to focus on three goals:

1. To facilitate the sharing of information among DD Councils and to identify common problems and issues which confront developmentally disabled citizens in rural areas;

2. To examine models of comprehensive service systems in rural areas; and

3. To examine selected rural programs concerning health care, services to children, services to adults, manpower development, client identification, transportation, and comprehensive services.

DD/TAS, through nominations solicited from the Rural Services Committee, the various state DD Councils, and other knowledgeable sources, identified exemplary rural programs for each of the six services listed in goal three above.

Each state DD Council was invited to send up to four participants. Actual attendance included 72 people representing 33 state DD Councils, plus those presenting and other guests, with more than 100 total participants registering.

The first issue addressed was that of defining "rural." In planning the workshop, it was decided that the only satisfactory approach was not to specify a definition, but rather to let each state make its own distinction regarding which part of its area might be considered rural. It later became apparent that wide discrepancies exist among definitions appropriate to different states.

In the information-sharing groups, many participants shared common concerns regarding: transportation problems; funding limitations; incompatability between popular service models with urban origins and the characteristics of rural communities; and the relative political weakness of rural areas.

The following papers, with one exception (Chapter 10 by Ted Bergeron) generally represent the content of each author's presentation at the conference.

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CHAPTER 1

WHO, WHAT, AND WHERE: STUDYING PREVALENCE OF DEVELOPMENTAL DISABILITIES IN WEST VIRGINIA

by

Dennis N. Lindberg

How many persons with a developmental disability live in rural areas? This chapter reports a study done in West Virginia designed to determine how many developmentally disabled persons need services. The results suggest changes in, or at least re-evaluation of, some traditional assumptions in planning.

Dennis N. Lindberg is a member of the faculty of Davis and Elkins College, Elkins, West Virginia and a member of the West Virginia Developmental Disabilities Council.

Introduction

This study was designed to meet the most pressing need in planning for the developmentally disabled of West Virginia - reasonably accurate statistics as to the number of developmentally disabled persons living in the state who are not in institutions, and their geographic and age distributions within the population.

Definitions. This is a report of a prevalence study. Prevalence means the rate at which a condition is found within a community, county, state or nation. In contrast, incidence refers to the rate of initial occurrence. So, for example, while it is reasonably well established that the overall incidence of Down's Syndrome (Mongolism) is 1 in every 600 live births, it is equally clear that the prevalence of Down's Syndrome is not 1 for every 600 persons in every population. While Down's Syndrome is thought to occur randomly, it has not been established that incidence in specific populations is not affected by social and environmental factors. Prevalence is further influenced by social and environmental factors. Health care, for example, is not of uniform quality in all localities or for all socio-economic groups. Hence life expectancy varies, for both normal persons and persons with Down's Syndrome. Migration affects prevalence as do attitudes toward institutionalization.

Incidence studies, then, look at the occurrence at birth of conditions, while prevalence studies look at their distribution within populations.

Planning for services and facilities for the developmentally disabled requires prevalence data - data concerning their social location within the population.

Who is developmentally disabled is a social question. Though a person may have a condition with a physical or psychological cause, that condition is transformed into a handicap only in the context of a social situation within which others define the condition as handicapping. If others in a community see a person as normal, then he is normal for all practical purposes, regardless of what clinical symptoms he might exhibit. Conversely, a person is substantially handicapped when he is defined as substantially handicapped by members of his family and the community in which he lives.

Developmental disabilities planning is directed towards normalization, that is, helping the developmentally disabled to lead lives that are as normal as possible. Hence, someone seen by his community as being normal cannot be said to be substantially handicapped or developmentally disabled. The definitions of what are mental retardation, epilepsy, cerebral palsy, autism, and similar neurological disorders used in this study are the everyday, commonsense definitions which structure the interactions of handicapped persons with others in the communities in which they live.

Methods. This study was conducted in the following manner. Socio-economic data from the 1970 Census was obtained for a random sample of 1/7th of he census enumeration districts in West Virginia. From these, 45 districts with a 1970 population of 35,142 were selected as representative of

the state. Interviewers (where possible natives or long time residents of these districts) were hired and trained. Between February and May 1975, every household in 25 of these 45 districts was visited in an effort to find every developmentally disabled person living in the district. The remaining 20 districts were surveyed in an identical manner in March and April of 1976. An interview schedule was used at the home of each disabled person in order to specify the nature of the disability and to obtain other relevant information. The results were coded, prevalence rates for each district calculated, and correlations with the socio-economic data from the 1970 census constructed. Multiple regression equations, which incorporate a number of correlations and are a technique for improving predictions (instead of simply taking the mean, or average), were developed and used to predict to the 1/7th sample. These predictions were then weighted and combined to produce the county and regional figures. The state figures are a combination, weighted by population size, of the regional figures.

Purpose. The purpose of the study was to provide persons who plan services for the developmentally disabled citizens of West Virginia with prevalence estimates drawn from data obtained in West Virginia. Currently, planning is based on prevalence rates derived from studies done by a variety of methods in a variety of places. These studies of individual disabilities are concerned with the mildly as well as the substantially handicapped, and do not take into account the multiple handicapped. The figures in the report of study are a considerable improvement over the figures currently used which assume a uniform distribution of the developmentally disabled throughout the nation and world.

Conclusions. Several important points are clearly demonstrated in the report:

- the non-institutionalized developmentally disabled are not distributed uniformly or randomly throughout the population of West Virginia;
- there is a considerable overlap between handicaps;
- the non-institutionalized developmentally disabled are concentrated in the younger age groups;
- the prevalence rates for developmental disabilities as a whole, and for persons substantially handicapped by particular disabilities are considerably higher in West Virginia than has previously been assumed.

The prevalence figures in the report may seem low at first glance. Two factors should be kept in mind, however, First, this study included only those "substantially handicapped" (handicap is a social meaning attached to a physiological or neurological condition). Secondly, the prevalence estimates for individual disabilities put forth by the national voluntary associations are based on statistical models which necessarily incorporate a preponderance of 'mild' or 'borderline' cases. While mental retardation has been estimated by the National Association for Retarded Citizens at 3% of the population, only 0.3% of the population is classified in the categories moderately, severely, or profoundly retarded. The remaining 2.6% are said to be mildly retarded. As the President's Committee on Mental Retardation has recently recognized, nearly 90% of those classified as mentally retarded, the mildly retarded who are multiple handicapped, are not developmentally disabled within the meaning of the law.[2]

Thus the West Virginia prevalence rate for mental retardation of 0.81% of the non-institutionalized population should be compared to The National Association for Retarded Citizens estimate of 0.30% for moderate, severe and profound retardation.

Similarly, the Epilepsy Foundation of America estimates epilepsy at 2% of the population and United Cerebral Palsy estimates cerebral palsy at 0.4%. As borderline or mild cases, those institutionalized, and, in the case of epilepsy, those controlled with medication have been excluded, our prevalence rates of 0.35% for epilepsy and 0.09% for cerebral palsy are again considerably higher than would be expected from making the statistical assumption of normal distribution.

In the age distribution data, evidence of the long term effects of improved health care, particularly antibiotics, is seen. Only 18% of the cases found were initially identified by the schools. Most were identified by the parents themselves or by medical doctors. Thus, the large concentration of developmentally disabled persons in the younger age groups is only minimally due to the effects of labeling by the schools, and is instead an indicator of the ever increasing life expectancy of developmentally disabled persons. Thus, there is a need for more community programs for adults as life expectancy increases, and for infant programs to insure the best possible start toward a life span that will increasingly approach the normal length.

The report of the study contains compilations of a number of kinds of data gathered in the survey. Among these are characteristics of individuals with developmental disabilities, each of the component disabilities, and of the multiple handicapped; proportions of persons with a particular disability; correlations between prevalence rates found in surveyed districts with socio-economic characteristics of those districts; projections of prevalence to the state, planning region, and county level; and age distributions of persons with developmental disabilities and the component disabilities. Comparisons between disabilities are facilitated through summary tables.

Space limitations prevent the presentation of all of this material in this chapter. Instead, a selection has been made from the data presented to indicate possibilities.

1. Multiple Handicaps. The proportion of persons having one of the developmental disabilities who also has a second of these disabilities is shown in Table 1.

Table 1

PROPORTION OF PERSONS WHO HAVE ONE HANDICAP
WHO ALSO HAVE A SECOND HANDICAP

		Who Also Have			
		MR	EP	CP-	OTHER
Percent of	MR	--	21.3%	4.7%	7.4%
Those Who Have	EP	48.4%	--	5.7%	9.0%
	CP	36.0%	19.4%	--	0.0%
	OTHER	62.5%	34.4%	0.0%	--

N=91

That 24.2% of the developmentally disabled located in this survey have more than one of the disabilities, indicates that prevalence figures for developmental disabilities cannot be arrived at simply by adding together figures for each of the component disabilities. Such a procedure would, based on this data, overstate the number of developmentally disabled by about one-third, and minimize the severity of the problems to be dealt with.

Table 1 clearly documents the interrelatedness of the major handicaps grouped together under the developmental disabilities. While mental retardation is the largest handicap in terms of numbers, significant numbers of those with mental retardation also have epilepsy and/or cerebral palsy. Substantial proportions of those with epilepsy and cerebral palsy are also mentally retarded, and there is a significant overlap between epilepsy and cerebral palsy.

2. Correlations. A principal working hypothesis of the study was that prevalence rates for the developmental disabilities would vary systematically with differences in various socio-economic characteristics. Three hundred and eighty persons with developmental disabilities were found in the 45 districts surveyed, which had a 1970 population of 35,142. The prevalence rate of developmentally disabled in the surveyed districts was thus 1.08% of 1970 population.

Table 2 shows, however, that there are systematic relationships between the developmental disabilities prevalence rates found for individual districts and their socio-economic characteristics as reported in the 1970 Census.

Table 2 indicates that higher rates of developmental disabilities are found in districts where income and education levels are low, where large percentages of the housing is substandard, which are rural, and where the birth rate is relatively high. The percentage of the population which is young or non-white are not important variables, and neither is family size or unemployment.

Table 3 summarizes correlations between socio-economic characteristics of districts and prevalence rates found for the major component disabilities, mental retardation, epilepsy, and cerebral palsy. For maximum clarity, only correlations significant at the .10 level are reported in Table 3.

Correlation coefficients indicate the strength of the relationship between two variables. A perfect correspondence is indicated by a correlation of +1, no relationship by.00, and an inverse relationship by -1. The larger the correlation coefficient, the stronger the relationship, whether positive or negative.

For developmental disabilities as a whole, mental retardation, epilepsy and cerebral palsy, the key indicators of high prevalence rates in a district are low income levels, low education levels for adults, relatively high proportions of sub-standard housing, relatively high birth rates, and that the district is rural.

Table 2

CORRELATIONS BETWEEN PREVALENCE OF DD AND SOCIO-ECONOMIC CHARACTERISTICS

Characteristic	Correlation With DD	Significant Level
% population rural	.3732	.006
% population non-white	.0958	
% population under 18 years	.1641	
% population age 65 and over	.2464	.051
median years of school for adults	-.4769	.001
mean children ever born to women 35-44 years of age	.3800	.005
% workforce unemployed	.0075	
% families with incomes over $10,000 per year	-.3175	.017
median family size	.0696	
% families below poverty level	.4307	.002
% housing lacking one or more standard plumbing fixtures	.5415	.001
per capita income	-.4531	.001

Table 3

CORRELATIONS BETWEEN PREVALENCE OF MR, EP, AND CP AND SOCIO-ECONOMIC CHARACTERISTICS

Characteristic	Correlation relation with MR	EP	CP
% population rural	.3536	.4207	ns
% population non-white	.2118	ns	ns
% population under 18 years	ns	ns	ns
% population age 65 and over	.2743	ns	ns
median school years for adults	-.4578	-.3319	-.4082
mean children ever born to women 35-44 years old	.3609	.2282	.3877
% workforce unemployed	ns	ns	ns
% families with incomes over $10,000 per year	-.3260	-.2063	ns
median family size	ns	ns	ns
% families below poverty level	.4759	.2407	.3256
% substandard housing	.5405	.3836	.3299
per capita income	-.4582	-.3571	-.2588

ns = not significant

3. Projections. Correlations, as presented in the previous section, are useful in understanding relationships between variables. Statistical evidence has been presented demonstrating relationships between developmental disabilities and the component disabilities and the socio-economic characteristics of the places where the disabled are currently found.

Multiple regression analysis, as used to generate the rates shown in this section, is a technique for using correlations to construct equations which predict values of dependent variables (the disabilities) from known values of independent variables (the socio-economic characteristics). Equations were constructed for developmental disabilities and each of the component disabilities which give the best possible predictions (within an acceptable level of statistical significance) of the actual prevalence rates in the 45 surveyed districts from the socio-economic characteristics of those districts. These equations were then used to predict prevalence rates for districts that were not surveyed. While not completely accurate, such predictions are substantial improvements over simply taking an average of all districts surveyed and applying it to the state as a whole, to all regions, and to all counties. West Virginia is not homogeneous. Using correlations to construct equations makes possible predictions which take into account the differences within the state and the differences in prevalence rates found in the survey.

Like many states, West Virginia is organized into planning regions. The criteria for drawing regional boundaries were principally concerned with shopping patterns, transportation networks including roads, patterns of service delivery, as well as the Appalachian Regional Commission's policy of encouraging the formation of growth centers as a developmental strategy for Appalachia. Thus regions as they exist in West Virginia are composed of an actual or potential urban growth center of small to medium scale and the counties which surround it.

While these regions may be adequate for planning purposes, they are not adequate for analytic purposes, as there are significant social and economic differences within regions, especially between the urban centers of some regions and the surrounding rural counties. Region III, for example, includes Kanawhy County (Charleston) with a strong mixed economy of state government, commerce, industry and mining; Clay County, perhaps the poorest county in the state, lacking mining, commerce, and industry, and with land capable of only modest subsistence farming; Boone County, heavily dependent upon coal mining, and Putnam County with more prosperous farming, no mining, and developing into a suburban area for Charleston to the east and Huntington to the west. Four more dissimilar counties could hardly be imagined. Sensible though it may be to look at the four in terms of the development of service delivery systems, it does not make sense to treat them as a unit in analyzing their current situations.

For the purposes of predicting prevalence rates, prediction regions were developed. The principal criteria used were similarity in socio-economic characteristics between counties, geographic similarity and similarity in long term population trends.

Regression equations were used to predict to 1/7th sample of the census enumeration districts of the state. These predictions were grouped by prediction region and weighted by population to produce prevalence figures for the prediction region as a whole. As the counties in prediction regions are relatively homogeneous, prevalence projections for prediction regions are used for the individual counties in the prediction regions. These county figures, weighted by population, are used to produce prevalence figures for the Planning and Developmental Regions.

Table 4 presents prevalence estimates for developmental disabilities for the State and the 11 Planning and Development Regions as a percentage of 1970 population. The number of cases estimated for 1976 is also shown.

Table 4 shows that developmental disabilities are not distributed evenly across the population of West Virginia. A region by region comparison of the percentage of cases with the percentage of population makes this evident, as does a comparison of the regional prevalence rates with the state-wide rate. The rate of Region VI, for example, is 21.8% less than the state-wide rate, while the rate for Region I is 27.3% greater.

The report of the project contains similar tables for the component disabilities, as well as projections for counties. This material is summarized in Table 5.

Table 4

PREVALENCE OF DD IN WEST VIRGINIA BY REGION

		%DD	#DD	% State's Cases	% State's Pop.
State		1.10	19,216	100.0	100.0
Region	I	1.40	3,320	17.3	13.7
	II	1.15	3,074	16.0	15.3
	III	0.90	2,609	13.6	16.7
	IV	1.33	1,635	8.5	7.0
	V	1.11	1,780	9.3	9.2
	VI	0.86	2,104	10.9	14.0
	VII	1.32	1,369	7.1	5.9
	VIII	1.29	767	4.0	3.4
	IX	1.13	751	3.9	3.8
	X	0.98	1,192	6.2	7.0
	XI	0.88	615	3.2	4.0

Table 5

SUMMARY OF PREVALENCE PROJECTIONS

	% DD	% MR	% EP	% CP
State-wide rate	1.10	0.81	0.35	0.09
Highest regional rate	1.40	1.09	0.43	0.10
Lowest regional rate	0.86	0.57	0.24	0.08
Highest county rate	1.50	1.15	0.48	0.12
Lowest county rate	0.76	0.50	0.24	0.07

4. Age distributions. The age distribution of persons with developmental disabilities and the component disabilities actually found in the surveyed districts was compared with the age distribution of persons in the state from the 1970 Census. While 37% of the state's population was under 20 years of age, 52% of the developmentally disabled persons, 53% of the mentally retarded, 48% of those with epilepsy, and 69% of those with cerebral palsy were in that age group. Prevalence rates developed for regions and counties were then multiplied by factors derived from these differences (1.41 for developmentally disabled, for example) to obtain prevalence rates for those under 20 years of age. Table 6 summarizes these rates.

Table 6

SUMMARY OF PREVALENCE RATES FOR PERSONS UNDER 20

	% DD	% MR	% EP	% CP
State-wide rate	1.55	1.16	0.46	0.17
Highest regional rate	1.97	1.56	0.56	0.19
Lowest regional rate	1.21	0.82	0.31	0.17
Highest county rate	2.14	1.64	0.62	0.22
Lowest county rate	1.07	0.72	0.31	0.13

Generally, high prevalence rates were projected for rural counties, with five southern counties, economically dependent upon the coal industry, having the highest rates. Low rates were projected for counties containing the major urban centers of the state. Kanawha county (Charleston) and the three counties with the northern cities of Clarksburg, Fairmont, and Morgantown generally had the lowest rates.

Two statistics are important for decisions regarding new programs: the absolute number of developmentally disabled persons in the area to be served, and the prevalence or relative severity of developmentally disabled in an area. While some areas have low prevalence rates, they have a large number of cases because they are heavily populated. Other areas have high rates and a proportion of the state's cases significantly larger than their share of the

population. While relative need cannot be the only criteria used in DD planning (program quality, agency competence, community support, and right to service are among the number of equally relevant criteria), it must be taken into account as long as funds for Developmental Disabilities programs are limited. Scarce resources must be concentrated in areas of greatest need.

Caution should be used in generalizing these results to other states. While there are bound to be similarities between West Virginia and other states, so too are there factors unique to West Virginia. The methodology of this study is generalizable, however. Replication in a number of states would provide a basis for making generalizations applicable to all states. While the implications and conclusions which have been drawn for West Virginia may seem intuitively correct or incorrect when applied to other states, their validity for other states will not be known until similar studies are done.

CHAPTER 2

SERVICE DELIVERY IN RURAL AREAS: CONTEXT, PROBLEMS AND ISSUES

by

Charles R. Horejsi

Approximately one-third of our total population lies in rural areas. These rural areas differ significantly from urban and suburban areas in many ways including: cultural norms, transportation, income levels, and professional resources.

These, and other differences as well, all have implication for the delivery of services to the developmentally disabled in rural areas. Yet nearly all well known service models are based on urban programs. It is uncommon to find programs planned specifically to meet the unique needs of handicapped people in rural areas.

In this chapter Charles Horejsi, Professor of Social Work at the University of Montana, Missoula, outlines some of the problems of service delivery that are unique to rural areas. He also presents some positive implications based on strengths common to rural communities.

Introduction

Efforts to develop community-based programs in rural areas must grapple with problems and issues somewhat different from those encountered in urban areas. Unfortunately, the special needs and problems of rural areas do not get much attention. Popp (1975) recently noted that the:

> . . . special needs of rural areas seem to have been neglected in the nation's efforts to recognize and cope with the problems of mentally retarded persons. When the federal government arranged in 1964 for 'comprehensive' state-wide mental retardation studies throughout the country, only a very few states ever mentioned the specific needs existing in rural areas. Yet rural areas still comprise a large part of the nation. . . (p. 129)

Cochran (1976) has offered convincing arguments concerning the existence of a pro-urban and possibly an anti-rural bias within various federal agencies, including the Department of Health, Education and Welfare. Copp (1970) made similar observations. This bias results from the fact that most of those in decision-making positions are from urban areas, now live in urban areas, have work experience in urban programs, received their professional education in urban universities and hear and read most about urban problems and programs. They are simply uninformed about rural areas. They are more familiar with what is going on in urban areas and how things work in urban areas. Or, if one wishes to view it from a behavioral point of view, one could conclude they have not been rewarded for paying attention to people from rural areas. Or, conversely, they have been rewarded for paying attention to urban areas.

A 1966 Wisconsin project identified a number of special problems relating to the development of community-based programs for mentally retarded persons in rural areas:

A. In a rural area the understanding and awareness of the retarded's needs and the subsequent impetus to serve him has suffered from the relative lack of exposure to publicity, information, and educational effort.

B. Services for the retarded have not developed in rural areas due to the mechanical problems involved in bringing people together in an area of low ponulation density.

C. In a rural area there is often a lack of facilities such as day care, sheltered workshops, and special classes to serve the retarded.

D. Most rural areas lack diagnostic and treatment centers.

E. Rural areas lack an organizational structure for proper identification, treatment, and referral of the retarded and their families.

F. There is an extreme lack of trained professionals, such as psychologists, social workers, public health nurses and physicians, who can offer service to the retarded or their families.

G. The rural retarded and their families have long been unaware of any alternatives to strict custodial care in the home.

H. People in rural areas often have low expectations for their normal child, as well as the retarded, and are unable to see the value of training and education.

I. There is often a stigma attached to family counseling in a rural area, and the fixed point of referral may be located in a clinic or welfare department. Where little stigma is attached, such as the public health nursing service, this office is understaffed in a rural area.

J. Neighbors in a rural area often have less experience with and understanding of the retarded child than their urban counterparts.

K. Parents of the retarded in a rural area are often poor and cannot afford the cost involved in transportation or the child care necessary to attend parent group meetings or take advantage of counseling and diagnostic services for their retarded child. (cited in Popp, 1975, pp. 129-130)

Ten years later, most of these problems still exist in rural areas. If services and opportunities are to be expanded for persons who are developmentally disabled and living in rural areas, planning and program development must be built upon rural resources and characteristics. Moreover, we need to re-examine our tendency to try and "export" urban planning concepts and urban programs into rural areas. Rather, our strategies and tactics must be individualized to local circumstances and the rural condition.

According to Mayeda (1971) several local and state characteristics must be considered in the development of a comprehensive service system for the mentally retarded. These are: (1) land area, (2) population, (3) economics, (4) professional resources, (5) organizational resources, (6) consumer or client characteristics and (7) transportation. The remainder of this chapter will focus on several of these factors and elaborate on some of the problems and issues of program development and service delivery in rural areas.

What is Rural Area?

In the United State three-fourths of the people live on about three percent of the land. According to Kahn (1973):

> About half the people of the country live in eight of the fifty states - California, Illinois, Michigan, New Jersey,

> New York, Ohio, Pennsylvania and Texas. Most of that half, furthermore, live in or just outside the big cities of the eight states. However, the other side of the story is that a large number of Americans live in nonmetropolitan areas.

About 64 million Americans, one-third of our population, live in nonmetropolitan areas. More precisely, they did not live in a Standard Metropolitan Statistical Area, i.e., a metropolitan area surrounding a city with a population of at least 50,000.

Essentially, a rural area is one which is characterized by a sparseness of population or a low density. In other words, it is a relatively large land area occupied by a relatively small number of people. A few facts and figures on my own state of Montana will serve to clarify this definition.

In physical size, Montana is the fourth largest state; it is approximately 550 miles long and 315 miles in width. The states of Iowa, Indiana, Kentucky, Maryland and New Jersey could all "fit" in Montana. The 1973 estimated population for the entire state was 721,000. About 50 metropolitan areas in the United States have populations exceeding the population of the whole state of Montana. Only 17 Montana towns have populations over 5,000. Only seven have populations over 10,000. The state's two largest metropolitan areas have populations of about 80,000 each. The third largest city has a population of about 35,000. Nearly every town with a population over 5,000 is at least 100 miles from a community of equal size or larger.

The Rural Condition

Increasingly, the rural community resembles urban or suburban communities (Warren, 1972). While traditional urban-rural differences are becoming blurred, remnants of a rural culture still exist. Rogers and Burdge (1972), for example, note that rural people (mainly farmers and ranchers) exhibit certain attitudes and values which are different from those of people in urban areas. In areas where rural culture still persists, it must be considered in planning and service delivery.

Rural culture and characteristics have obvious relevance to the design and management of services in accord with the normalization principle. Bronston (1976) states that:

> The essence of that principle requires the use of culturally normative means and methods . . . to offer a person life conditions at least as good as the average citizen . . . and as much as possible enhance or support his/her behavior experiences, status and reputation. By culturally normative means, we speak about using those techniques, tools, media, and methods that are most familiar and valued in our culture. (p. 495)

Since the application of the normalization principle is "culture specific," it is interesting to ponder questions such as: (1) What are the "normal" conditions of the average rural citizen? and (2) To what extent should programs in rural areas incorporate the life experiences, values and expectations of

rural people?

Ginsberg (1976) has identified a number of conditions which are "normal" for the typical rural American. Some are the following:

> Rural dwellers often lack access to high quality education, highways, museums, libraries and entertainment . . . In a small town the choice [of entertainment] may be between a few bars and one movie.
>
> There is simply not much to do with one's free time . . . The rural wealthy may take world cruises or fly to a city for the weekend but the rural dweller of moderate means lacks such choices.
>
> If one is seriously ill the nearest urban hospital may be used, with all the attendant problems of transportation, isolation from family and friends and the added expense.
>
> Some small towns have no physicians or dentists. Others must rely on circuit riding healers, who serve each of several small towns one or two days a week . . . Still others must make do with less adequately prepared professionals than they could find in cities.
>
> Rural communities tend to be one or two industry or company towns [e.g., farming, agribusiness, mining]. Frequently, the industries are unattractive to young men and women.
>
> Many rural areas, perhaps most, lack efficient, low cost public transportation. But the available jobs may be miles away. Thus, ownership of an automobile is often a necessity for a worker in a rural area.
>
> One has little difficulty in finding overt racial segregation, lack of suffrage, corruption . . . Rural governments are often run by the local power structure much in keeping with the descriptions . . . found in the writings of Floyd Hunter (1969). The Lions Club, Rotary Club, Methodist Church and city council are frequently governed by the local wealthy citizens, no matter who the officially designated presidents, mayors or councilmen are.
>
> American Indians, Chicanos, and Blacks continue to report being singled out for special punishment by local law enforcement officials who are products of the same power elite that control everything else . . . no case is being made to support the idea that rural officials are less concerned about human rights than their counterparts in cities. However, cities have a number of other institutions such as civil rights organizations, legal aid agencies and government offices that conduct monitoring activities that, in

> turn, make officials more responsive to the protection of human rights and less inclined to act inappropriately. Rural communities are too small to support such institutions.
>
> . . . the church plays a major role in rural communities, perhaps a greater one than in urban areas. One's religious affiliation is an important consideration for newcomers to small towns.
>
> Impersonal services are uncommon in a setting where everyone knows everyone else or at least everyone else's relatives.
>
> . . . taking social or political positions that differ from those dictated by the conventional wisdom of the rural community may lead to social and professional ostracism.
>
> Those who are too quick to tell others their faults are unpopular in both the metropolis and the village. But the results of such behavior are more rapid, persuasive and dramatic in the [rural community]. (pp. 3-7)

What does all this mean? It means that there are both positives and negatives associated with most rural characteristics and norms. It does not mean that those of us interested in expanding services for the developmentally disabled should unquestionably support all rural norms. We must, however, be able to understand and accept those norms and work for change at a pace acceptable to the rural people themselves.

The Formal and Informal Services of Rural Areas

Recent contributions to social service literature (see, for example, Buxton, 1973; Segal, 1973; Koch, 1973; Mermelstein and Sundet, 1973; Miller, 1976) have identified several features of service delivery which are unique to rural areas. The literature also indicates that strategies and programs developed in urban areas cannot be simply "transplanted" into rural areas or small towns.

While it is true that rural communities have fewer formally organized professional services and agencies, it is a serious error to assume that a particular service is not being provided simply because a formal organization does not exist to provide that service (Ginsberg, 1973). It is important to remember that informal systems of service are common to rural areas. Patterson and Twente (1971) term these informal arrangements "natural service systems" or "natural helpers." More recently, the National Association of Social Workers has published a book on natural helping networks (Collins and Pancoast, 1976). These natural service systems include neighbor helping neighbor, loans among friends, service club involvement in helping specific families or specific handicapped individuals, hiring of people who need a job rather than people who have the skills, etc. These informal arrangements tend to develop in the absence of formal services. The rural professional must win access to the natural service system and insure that his or her formal and agency-based approach works in accord with the informal arrangements. This means developing and nurturing friendly relationships with local ministers, physicians, teachers, service clubs, agricultural extension agents, community

leaders, etc. It has been observed that service clubs play an especially important role in the informal delivery system at the local level (Ginsberg, 1969). These informal networks lack the sophistication and knowledge base of professionally organized programs but they do perform a valuable function and are usually "supported" by the influential citizens and community leaders making up the power structure. If a new formal plan for the development of human services poses a threat to these informal service structures, it may encounter considerable resistance. However, Wylie (1973) has observed that this informal helping network may be more of an asset than a liability in developing a new formal service system in rural areas.

> Here is a mighty resource for the social planner, a pool of people accustomed to helping each other, a pool of people already accepted and identified by the community as helping agents, and people who can be easily identified . . . the challenge is to strengthen and expand this natural network by preserving the naturalness rather than imposing professional standards and norms. In other words, . . . what we have there already may be quite good in its own right. (p. 26)

Despite some obstacles to change in rural areas, unique potentials are also present. One is the sense of pride and community spirit that exists in many rural areas. These elements are especially strong in relation to self-help activities and "taking care of our own." If new program ideas and plans are generated from within the community and are supported by respected citizens, the rural community is capable of rapid and surprisingly innovative action. On the other hand, plans or programs which are imposed upon small communities by "outsiders" often meet with passive resistance or fail to win support necessary for implementation. Thus, it is essential that parents, "natural helpers" and members of the power structure be involved in any planning process which affects rural communities. Not only is their involvement necessary to win acceptance of new concepts and new programs but many of these same individuals are needed to form the nucleus of volunteers which are so necessary to rural programs. As one might expect, it is no small task for regional or state planners to strike a balance between a community's unique desires and values and the bureaucratic requirements of large scale social planning and funding constraints.

Those wishing to escape the urban scene should not move to a rural community expecting an uncomplicated life. The dynamics of rural communities are far from simple. According to Ginsberg (1969):

> Rural communities are often as sociologically complex as urban communities. Many of their characteristics may be based upon little remembered but nevertheless influential historial events focused on family conflicts, church schisms, and a variety of other occurences which may deserve the status of legends. (p. 30)

Unless someone in the community chooses to inform you of these "historical events," you may live in a community for many years and remain baffled at the local behavior and the patterns of cooperation and noncooperation.

The "history" of interpersonal relations in the small community has an obvious effect on service delivery. Who runs or staffs a program may have much to do with whether or not a particular service is utilized by particular families. Thus, in the selection of staff, their personal background or "image" in the community is of critical importance, sometimes of more importance than their professional competence.

The provision of services on the Indian reservations common to many rural areas presents an even greater challenge. Cultural difference and inter-tribal conflicts can completely baffle the white, middle class professional or social planner. The usual approaches to service delivery and notions of professional/client relations are contrary to the tradition of noninterference. Good Tracks (1973) explains noninterference as follows:

> In native American society, no interference or meddling of any kind is allowed or tolerated, even when it is to keep the other person from doing something foolish or dangerous. When an Anglo is moved to be his brother's keeper and that brother is an Indian, therefore, almost everything he says or does seems rude, ill-mannered or hostile.
>
> . . . the Indian child is taught that complete noninterference with all people is the norm, and that he should react with amazement, irritation, mistrust and anxiety to even the slightest indication of manipulation or coercion. (pp. 30-31)

The value we place on early intervention, crisis intervention, behavior modification, parent training, advocacy, etc. indicates that most of us have been taught that interference is acceptable, even desirable.

The Rural Family

It is difficult, perhaps impossible, to formulate valid generalizations about the rural family. Clearly, rural families are experiencing the same stresses and strains that affect all modern families. Yet there are hints that there are a few differences between urban and rural families. Rogers and Burdge (1972) state :

> The family is changing, but rural families have tended to lag behind urban families on many of the trends and changes taking place. For example, rural families are still larger in size than urban families; they have retained more of the traditional family functions, are more father-centered and have fewer divorces. (pp. 194-195)

Our approaches to service delivery should recognize such difference and build upon them. Berkley (1976), for example, has observed how the tradition of hospitality can be utilized in gathering research and diagnostic data from rural families.

> Refusing hospitality is a gross mistake in a rural setting. I was always served tea or coffee and frequently was invited to stay for meals. Mealtime is usually the only time the

> entire family is assembled at once. The atmosphere around the table is much more relaxed and decidedly more information can be obtained . . . than in a formal interview setting. (p. 3)

Berkley also states that many rural families felt their developmentally disabled child was fairly well accepted by community people.

> . . . this observation seemed to come more from persons who had lived in the community . . . for a relatively long period . . . and had established good community relationships . . . There also seems to prevail an air of the 'extended family' in rural settings - emotional and psychological support of a family who has a handicapped member comes from friends and neighbors - as contrasted to our 'professional extended family' that exists in large urban settings in the form of specialized services and . . . professionals. (p. 6)

Because formal human service organizations are few and far between, many rural families have had little or no experience with such organizations. Many do not know how to find or utilize the few services that do exist. Thus, quality information and referral service and the professional roles of social broker and advocate-ombudsman take on added importance in rural areas.

Confidentiality In Service Delivery

Because of the relatively small number of people living in rural communities, the residents know just about everyone around.

> Scrutiny of everyone by everyone else is often characteristic of rural communities and what one does in his or her spare time, in the evenings and on weekends, is often a matter of public concern and discussion. (Ginsberg, 1973, p. 9)

That lack of privacy and anonymity presents some obvious problems for both the client and the professional.

The client or potential client may worry that everyone will know that he/she is seeking professional help. So long as the services sought are for rather tangible problems (e.g., physical therapy, medical treatment, etc.) there seem to be few conflicts. If, however, the individual needs professional help with personal or family problems, social or emotional ones, he/she may avoid being seen at agencies or offices providing such assistance. While working in a rural area of Colorado, this author observed that some individuals and families preferred to drive 50 or 60 miles to a "strange town" in order to keep appointments with traveling mental health teams even though the team was in their own community on a regular basis.

The rural professional is often placed in the rather awkward position of serving on committees or attending social and community gatherings with his/her clients. This can make both client and worker a bit uncomfortable, especially if they have shared highly personal matters.

Professional Resources

Rural communities can rarely support or afford a variety of professionals with specialized knowledge or skills. Thus, as is true for most human service professionals in rural areas, the professional working in rural programs for the developmentally disabled is forced by circumstances to become somewhat of a generalist. Few are able to specialize. Most rural professionals work with clients having a wide variety of problems and needs and most must carry administrative, planning and community organization responsibilities in addition to direct service duties.

The author has observed a fairly high rate of burn out among professionals in rural areas, especially those who must do extensive traveling. Burn out is probably also related to the breadth of their duties and feelings that they have to know a little about everything but are denied the satisfaction of feeling they are really competent in one special area.

Because specialists are not available and because rural professionals have fewer opportunities to function as members of teams they need to have a broader knowledge base and a greater range of skills than their urban counterparts. Very important skills are those related to the training and utilizing of the volunteers and paraprofessionals who must often carry heavy responsibilities in rural programs. Programs in continuing education and staff development are vital to agencies which are staffed by many nonprofessionals and by professionals who must carry a wide range of responsibilities.

It is also important to note that the professional in rural areas must often assume roles quite unlike those he might have in a large metropolitan area. In comparison to urban areas, rural area residents place less value on professional credentials and "expert opinion." Whether or not a professional's suggestions are accepted often depends on his informal behavior and how he relates to "ordinary people" in social situations.

Because many professionals live and work in small, isolated communities, they often suffer from loneliness and a lack of professional stimulation. Supervision and consultation are often unavailable. Professional organizations are generally weak because of the small number of professionals in any one community and the great distances between communities. Agency libraries, if they exist at all, are usually inadequate.

Because so few agencies offer employment opportunities, rural workers are understandably reluctant to engage in actions which might jeopardize their jobs (e.g., advocacy, public criticism of the "system," etc.). A protest resignation or an involuntary loss of one's job because of "boat rocking" often means that the worker must abandon employment in the human service field or leave the state to secure similar employment.

Unusual dress and unorthodox behavior can have an immediate and devastating effect upon a professional's ability to function in the community. Community acceptance is precious and essential to the rural practitioner, and it must be nurtured constantly. Community acceptance comes slowly and is based almost entirely on personal and informal behavior rather than professional credentials, previous experience or formal education. A newcomer to an area is always treated

as an outsider. It may take years before he or she feels a part of the community.

Economic Issues In Rural Areas

It is commonly assumed that a "unit" of social or human service costs about four times more in a rural area than in an urban area. This unit cost includes both the direct or indirect costs to the client (e.g., fees, time away from work, travel expense) and the agency. The expense of travel by staff and/or clients are key factors which increase the cost of service.

A lack of coordination among community programs is a common problem within all human service networks, including the developmental disabilities service system. A major cause of this problem is the multiple sources of private, county, state and federal funding utilized in the provision of services. Each source has guidelines which regulate the use of funds, the type of service which can be provided and eligibility. Thus, coordinated funding appears to be a prerequisite for a coordinated service delivery system.

The small number of developmentally disabled persons in any one community makes it economically unfeasible for all communities to develop a comprehensive service system. Rather, services must be regionalized. Ideally, they should be planned and administered at the regional level (Scheerenberger, 1974).

For the rural area, regionalization means the utilization of some type of multi-county organization. Given the fact that most rural communities and countries are rather provincial in their outlook, the creation and maintenance of such an organization can be a frustrating administrative experience but a good education in courthouse politics.

Organizational Resources in Rural Areas

Purchase of service contracts are commonly used to provide public funding to private organizations. Gilbert and Specht (1974) note that the purchase of service funding mechanism has both advantages and disadvantages.

> The major virtue of these forms of subvention to private and voluntary organizations is that they provide a varied means for starting government programs quickly. They avoid the rigidities of civil service and bureaucracy. Such characteristics are advantageous for public programs for small special groups of clients and for experiments or demonstrations.
>
> For the voluntary agency, the obvious advantage of these arrangements is access to the public coffers as additional sources of income. But they pay a price. To the extent that voluntary agencies are supported by government funds, they forfeit some degree of autonomy. Consequently, these agencies are limited in their ability to function as agents for the expression of new or unpopular ideas, as critics of public services, and as the guardians of pluralistic values. In the extreme, voluntary agencies may simply become an instrument of government policy. (p. 150)

In rural areas the flexibility of this mechanism is especially attractive because it permits the shaping and molding of programs to fit local situations, traditions and values. As previously indicated, programs designed and operated by local people are more likely to be accepted and supported by the community even though they are state funded. The community tends to view them as "out programs." By comparison, state operated programs have a harder time winning community support.

The purchase of service mechanism does, however, face some special problems in rural areas. The approach presumes that private human service organizations exist and that they are capable of modifying or expanding their program so as to provide purchaseable services. Well established private agencies are rare in rural areas. Those that exist tend to be small and fragile. Many are operated and staffed by volunteers or have a paid staff of one or two people. Because they frequently lack adequate professional resources, these organizations are seldom capable of planning and developing the sophisticated training and behavioral shaping programs needed by the more severely retarded or those with behavioral problems.

Not infrequently, agency board members and key decision makers within these small organizations are unaware of successful programs in other parts of the country. Innovations or program changes are more likely to be based on the experience of a program in a nearby community than on ideas derived from national conferences or from professional literature.

In some cases, a new nonprofit corporation is created for the specific purpose of securing public funds for the provision of badly needed services. Unfortunately, a newly created organization must devote most of its time and energy to maintenance functions. Only after it "gets on its feet" is it capable of devoting full attention to providing service. Thus, a new private service organization in a rural community may have a difficult time adhering to performance standards established by the state funding agency. This places state agencies in an awkward position of funding programs which leave much to be desired in the way of quality services.

ARC's (Associations for Retarded Citizens) and other self-help or consumer groups in rural areas, are usually small and relatively weak. Physical distance between families and the reality that there is a finite limitation on human energy and commitment makes it difficult to muster and maintain a stable advocate organization. In another example from my own state, the ARC has two paid staff members, an Executive Director and a Secretary/Assistant. That is not much of a staff to cover a large state. Travel budgets are phenomenal.

Conclusion

Rural areas are different from urban areas. Programs and services developed in metropolitan areas and designed to serve persons living in urban areas, simply cannot be replicated or "transplanted" in rural areas or in a small community. Rural-urban differences must be recognized. Planning and service delivery in rural areas must be built upon the rural culture and characteristics.

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CHAPTER 3

KITTENS VERSUS CATS

by

Roger Harper and Robert Schalock

'Kittens versus Cats' presents some strategies for developing effective rural programs, with emphasis on problems specific to developmental programs for adults. The chapter challenges the frequent assumption that rural areas can not develop complex programs.

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Rural DD Service Delivery Systems face unique problems related to financial resources, transportation, limited professional generic staff, availability of trained personnel, limited existing facilities and a sparse and usually scattered population. These problems combined with a frequently held fictionalized caricature of what "rural" really represents often creates a substantial barrier to the development of service delivery systems. The existence of some superb, fully accredited rural programs attests to the fact that in spite of unique problems rural programs can and should be developed. We will discuss an effective strategy to develop rural programs later in this chapter, but if we could at this time assume that even if a given rural area had no problem with funding, it could still fall prey to the biggest and most chronic problem associated with services to adults. This problem is encapsulated in the frequently used aphorism "everyone loves a kitten and no one particularly likes a cat." It is easy to see that child development programs based on the developmental model (kitten) are more warmly received by the public than sheltered workshops (cat) for adults. The implications of accepting one of the other of these models are obvious if one compares the assumptions and attitudes underlying each:

"Kitten Model"	"Cat Model"
Expect Changes	Don't Expect Changes
Accelerate Growth Potential	Declining Growth Potential
Educational Programs	Maintenance Programs; Limited Exits
Defined Exits	No Age-Appropriate Materials
Age-Appropriate Materials	Low Staff-Client Ratio
High Staff-Client Ratio	Potentially Dangerous
Cuddly and Defenseless	

Perhaps because rural DD programs have unknowingly accepted the "Cat Model", or because of those unique problems mentioned above, rural areas have generally not taken the time or money to develop, for adults, alternative systems to the traditional sheltered workshop. The purpose of the current paper is to demonstrate that by divesting oneself of both the "Cat Model" and the sheltered workshop - large group home concepts, an adult program, can be developed that fosters individual growth and results in client placement. Obviously, one's children's program should also follow a developmental model. For rural areas that do not have the population base to support a Developmental Center, we would highly recommend a Homebound program modeled after the Portage (Wisconsin) project.

The essential characteristics of the Mid-Nebraska program include the following: first, it embraces a developmental model for adults; second, it is client centered with identified progressions toward defined exits; third, it provides the client and staff with one consistent message during the program day; fourth, it provides age-appropriate materials that allow staff to assess client strengths and weaknesses, to develop remediation strategies, and to evaluate systematically client progress.

The Adult program is divided into three tracks ("Three Track System") including Basic Skills, Independent Living, and Competitive Employment. The progressions for each track are presented below and reflect an attempt to organize our philosophy into program alternatives. The alternatives are arranged in a hierarchy, weighted to the degree of normalization.

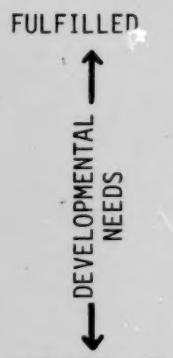
Basic Skills

PERSONAL INDEPENDENCE

Functional and Adaptive Behavior
Response/Skill Acquisition
- Sensory-Motor
- Auditory-Visual Processing
- Symbolic (including Language)
- Self Help

Response/Skill Deficits

PERSONAL DEPENDENCE



By acquiring the above mentioned skills, clients can then move toward the two defined exits in the adult track through the following progressions:

Independent Living

TOTAL SOCIAL INDEPENDENCE

Individual Living
Shared Apartment
Staffed Apartment
Alternative Living Units
Group Living-Small (2-5 Residents)
Group Living-Medium (5-10 Residents)
Group Living-Large (10 + Residents)
Nursing Home
State Institution

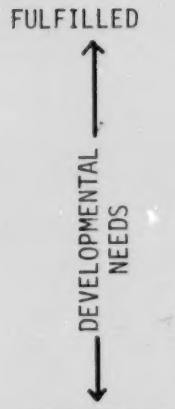
TOTAL SOCIAL DEPENDENCE

Competitive Employment

TOTAL ECONOMIC INDEPENDENCE

Full-Time Employment
Permanent Part-Time (Several Jobs)
Part-Time Employment (Odd Jobs)
Home Industries (Integrated with Community)
On-The-Job Training
Work Training (Competitive Employment Track)
Sheltered Employment
Work Activities
Inactivity

TOTAL ECONOMIC DEPENDENCE



The three tracks are operated in each of the seven area programs comprising Mid-Nebraska Mental Retardation Services. Each track has its own staff, program components (including screening test and remediation-teaching manual), location and suggested exits. Programmatically, target behaviors are assessed by staff when the client enters each respective track. Deficit target behaviors are then remediated through systematic prescriptive programming. Progress is monitored graphically through reassessment of the originally assessed target behaviors. Sequentially, adult clients move from:

Basic Skills focuses on remediating response deficits relative to sensory-motor functioning, auditory-visual processing, language, symbolic operations, and social-emotional development. Independent Living, which is taught during a full program day in the setting of the community residences, focuses on independent living skills including personal maintenance, clothing care and use, home maintenance, food preparation, time management, social behavior, community utilization, communication and functional academics. Competitive Employment training occurs either at a job training center or on-the-job and teaches job related skills, responsibility toward work performance, behavior in the job situation, and personal appearance. Copies of the Screening Tests and Teaching Manuals are available from: Mid-Nebraska Mental Retardation Services, 518 East Side Boulevard, P.O. Box 1146, Hastings, Nebraska 68901.

The three track system has been in operation for 2-1/2 years. During that time, we have experienced the development of a non-contract oriented program with the highest number of placements and lowest amount of attrition in placement annually in the state. In addition, the program not only places people in competitive employment, but also attends to independent living training and placement. It has been our experience that Independent Living

training is not only a vastly more complex subject than Competitive Employment, but also is a primary prerequisite to successful vocational placement. In addition, the program has seen skill acquisition in all clients, with the greatest acquisition percentage in the lower IQ groups. And finally, the program has truly planned for, and succeeded, in implementing deinstitutionalization.

In conclusion, although we have used this forum to focus on one basic problem found in the establishment of DD services that is not necessarily unique to the rural area, we firmly believe that just to have some services in the rural area is only "half a loaf" and because we are few in number, we don't necessarily have to be poor in quality. It has been our experience that despite numerous problems, which are frequently overly stressed and sometimes become justifications for the low priority given to rural programs, the fact is that with sufficient funding, rural areas can develop viable programs for serving handicapped citizens of the area. The first task is to believe it can be done, and the second is to mobilize parents to demand from their state legislators the money to provide for normalizing and developmental programs. This process makes use of a local lobby of parents and relatives who sensitize the legislator to the unmet need and apply a constant pressure until the lawmaker indicates that he too feels DD is a high priority along with some peace and quiet on the home front. The analogy of the "starfish and oyster" is appropriate here. The starfish (like the parent) knows that there is something he wants very badly from the oyster (which in this case would be the State). Although the oyster has an impervious shell to protect him and stronger muscles to prevent the starfish from opening the shell, the oyster will always be the loser, simply because the starfish can apply two fresh arms when the ones he has been pulling with tire, whereas the oyster cannot. By using lesser strength for a longer period of time, the starfish is assured success. After funds are available, one needs to come to grips with the developmental model, including prioritizing levels of least restrictive alternatives and developing programs to implement them. Although standardization of programs, as described above, contains dangers related to potential stagnation and pedantic approach, it has been our experience in dealing with the mentally retarded that mixed program messages are confusing to the client and require excessive program competencies of the staff. We therefore embrace a singularly simple approach to a very complex and difficult challenge. We offer this paper as a sincere effort to share our experiences with others in the rural areas and feel a communication bridge must be established in order to overcome the self-fulfilling prophecy that rural areas cannot cope with the complexities of establishing viable DD service delivery systems.

CHAPTER 4

DEVELOPMENTAL DISABILITIES

MANPOWER DEVELOPMENT IN RURAL AREAS

County Agents Model

by

Floyd Dennis

The County Agricultural Agent represents a model of service delivery that has been viewed as highly successful. An attempt has been made in several Tennessee counties to adapt elements of that model to serving the needs of children, including developmentally disabled children.

This program is described by Floyd Dennis, Community Program Coordinator at the John F. Kennedy Center for Research on Education and Human Development at George Peabody College for Teachers.

Living in our society is a complex process. Whether one lives in a rural or urban setting, relationships to people and to things[1] are far more numerous and demand far more ability than in past generations. At the same time the close personal, interdependent and supportive relationships that existed in our more bucolic past have been diluted. Fast transportation, changes in housing and family patterns, altered production and commercial practices, and increased professionalization of all sorts of activities have contributed to this dilution.

Even the Supreme Court of our country has recognized the increasing complexity of relationships by observing that "it is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of (formal) education."[2] The point is this: adapting to the complex relationship involved in today's environment is a difficult task for those without developmental disabilities; it is even more difficult for persons with developmental disabilities. Assistance from others is particularly vital to them.

Wolf Wolfensberger and others,[3] looking at the roles of those who provide assistance have pointed out the importance of seeing the helper's role as involving two classes of functions. One of these, the instrumental function, involves acting as an instrument to do something the protegé cannot or does not do for himself. Changing a diaper, preparing food, delivering the protegé to necessary health services, providing exercises and washing clothes are all examples of functions encompassed within the instrumental role, in other words, the instrumental functions helpers perform are those which solve practical problems of life such as bathing children, washing dishes, attending health needs or earning a living.

The other aspect of a helping role involves the expressive or affective functions. These are performed by relating to the emotional or spiritual needs of the protegé. The hug, the pat on the back, "very good," "I love you," "you can do it," are common tools of the expressive role. In other words, the expressive functions involve the exchange of affection that meets deep seated needs and that often makes instrumental demands meaningful or bearable.

In simpler times past, developmentally delayed and developmentally disabled people had easier access to a larger nuclear family, including grandmothers, uncles, sisters augmented by easily accessible neighbors who could contribute to performing both instrumental and expressive functions. Now, because of dispersal and living styles that require less personal interdependence, this resource pool is substantially diminished. Consequently, the resulting deficit must be met in other ways or go unmet.

The process of integrating and maintaining individuals in American society commences before birth and continues throughout adulthood. It involves at least three sets of systems that have evolved for that purpose. These three sets of systems may be referred to as the Key Integrating Systems of Society (KISS), the In Trouble Systems (ITS), and the Institutional Care Endeavors (ICE).[4]

In addition to the nuclear family, the Key Integrating Systems include the Health System, Neighbors or Community Groups, the Education System, Community Residential Programs, and perhaps Churches, Boys Clubs, and other agencies (depending upon the scope of the adjective "Key"). The In Trouble Systems include the Law Enforcement System, the Court System, Welfare and other Social Service Agencies, Area Mental Retardation Programs, Diagnostic and Evaluation Programs, Vocational Rehabilitation Services, and so on. The Institutional Care Endeavors include facilities for juvenile delinquents, psychiatric hospitals, prisons, residential schools for the handicapped, such as blind, deaf and retarded citizens and perhaps other specialized residential facilities which are to some degree insulated from the common society.

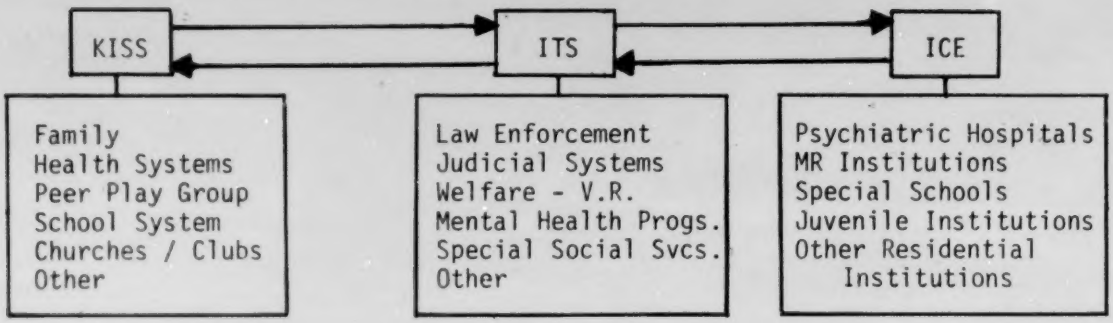
It is the role of the Key Integrating Systems of Society to assist each child and impaired adult to develop those elements of behavior required to adapt to the demands of society at the level of complexity our society expects in each stage of the person's development. This is done by teaching coping skills (e.g., walking, speaking, reading, socializing, etc.) and by eliminating those behaviors which are seen as deviant at certain stages of development or in certain situations (bedwetting, crying, thumb sucking, acting out, etc.). From a prevention standpoint, the Key Integrating Systems can be seen as charged with eliminating behavior (or dependency) inappropriate for the developing person's life stage. If the person fails to repond within the degree of tolerance of the Key Integrating Systems, he is generally given additional labels (e.g., unruly, delinquent, disabled, dependent, deaf, autistic, emotionally disturbed and the like). This label generally signals a turning to the In Trouble Systems to assist in bringing the behavior under control or it signals an abandonment by the Key Integrating Systems of some or all of the instrumental and expressive functions regarding the person labelled. With a degree of frequency many experts in human development are beginning to question, the use of In Trouble Systems (or shifting the burden to In Trouble Systems) too often results in assigning to the Institutional Care Endeavors the responsibility for continuing virtually all of the needed instrumental and expressive functions at a place apart from where the Key Integrating Systems function. Thus the child or disabled person is extruded from the Key Integrating Systems and into the In Trouble Systems or the Institutional Care Endeavors.

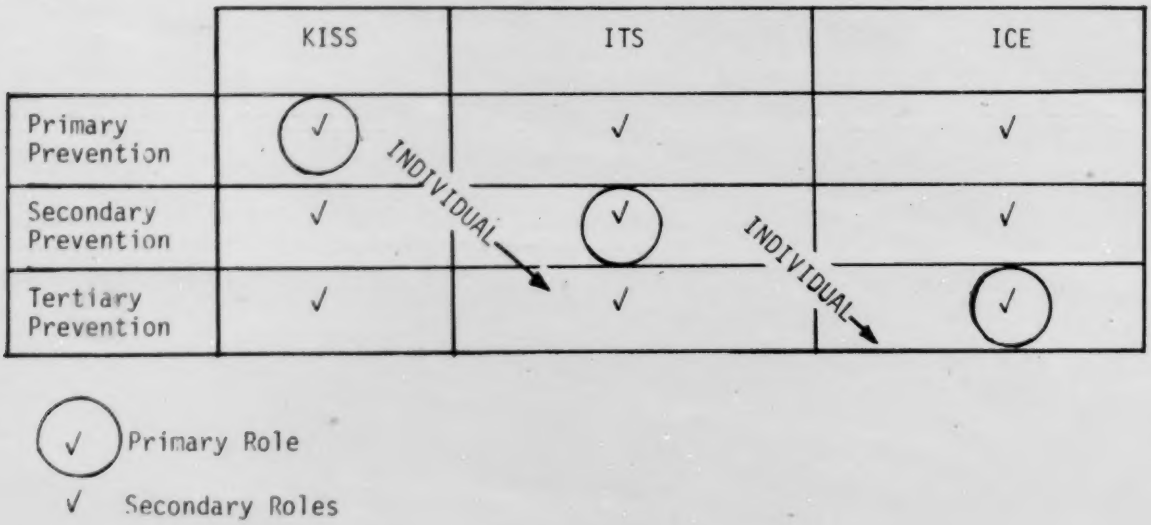
In order to assist the reader in visualizing the foregoing proposition systematically, Figure 1 seeks schematically to present the three sets of systems and some of the concepts on how they are grouped, how they interface, and how children move from one to the other. Once we agree to visualize the systems in this way, we can proceed more systematically to look at manpower needs for achieving appropriate goals for services to developmentally disabled citizens.

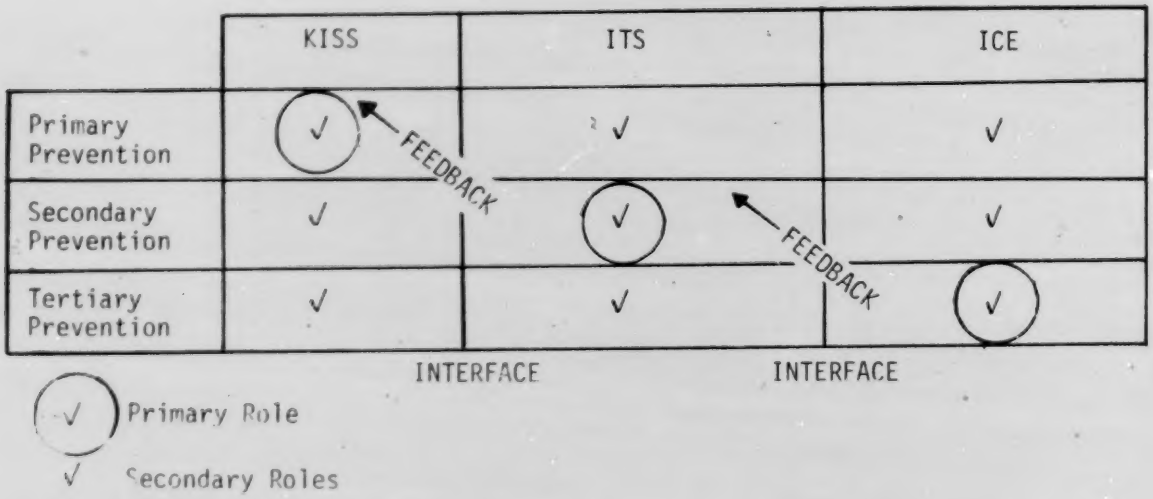
It is now generally allowed that all human beings, including those with developmental disabilities, are developing organisms.[5] They develop through predictable stages and each of these stages involve predictable and often critical decisions and tasks. Always, the overriding goals are:

a) to increase the complexity of behavior of the disabled person
b) to increase the control over the environment by the disabled person, and
c) to promote the ordinary human and social characteristics of the disabled person.[6]

Figure 1


KISS
ITS
ICE
Family
Health Systems
Peer Play Group
School System
Churches / Clubs
Other
Law Enforcement
Judicial Systems
Welfare - V.R.
Mental Health Progs.
Special Social Svcs.
Other
Psychiatric Hospitals
MR Institutions
Special Schools
Juvenile Institutions
Other Residential
Institutions


KISS
ITS
ICE
Primary Prevention
Secondary Prevention
Tertiary Prevention
INDIVIDUAL
INDIVIDUAL
√ Primary Role
√ Secondary Roles


KISS
ITS
ICE
Primary Prevention
Secondary Prevention
Tertiary Prevention
FEEDBACK
FEEDBACK
INTERFACE
INTERFACE
√ Primary Role
√ Secondary Roles

Experience seems to teach us that these goals can be met better if we utilize the patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society. Looking at Figure 1 representing the Key Integrating Systems of Society, the In Trouble Systems and the Institutional Care Endeavors we can see that the Key Integrating Systems of Society have access to and can utilize naturally occurring patterns and conditions of everyday life with less effort than the Institutional Care Endeavors. This suggests that allocation of manpower and other resources to intervene to promote the goals of increased independence and integration for developmentally disabled citizens is affected by whether the actors are based in a Key Integrating System, the In Trouble System or the Institutional Care System. Given the same amount of skill and energy, one working out of Key Integrating System might well utilize naturally occurring events and opportunities to meet the instrumental and affective needs of developmentally disabled citizens with less expenditure of man-hours because the "get-ready," "put away," coordination and logistical tasks are less. For instance, assisting a developmentally disabled child or adult to learn to operate an ordinary kitchen, dining room, bedroom or bathroom requires far less get ready time in a family residence or apartment than in an institution designed to serve large numbers of handicapped individuals. Likewise learning to use public transportation or learning to get about safely in a community shopping district can be achieved with less expenditure of manpower from a system situated in the community where the developmentally disabled person will ultimately function than in one removed from the place of ultimate function.

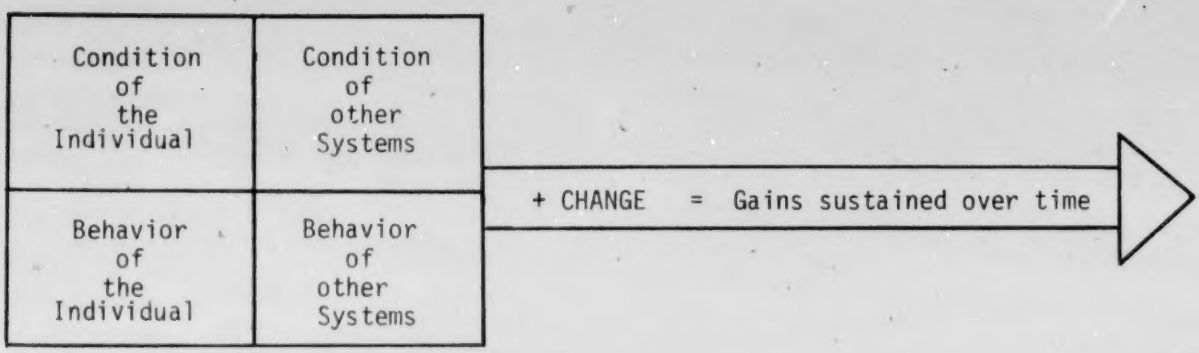
On the other hand, it could be argued that the task of assuring a life of optimum independence and integration into society for developmentally disabled persons involves more than changing the behavior and the conditions of the person himself. Not only must we seek to alter the impairing conditions of the developmentally disabled persons and to promote more complex behavior and skill to assure successful adaptation, we also must eliminate disabling characteristics and behavior presented to that person by the significant other places, people and things in his life. This argument might continue with the proposition that specialized residential facilities with specially designed equipment and specially trained people can sufficiently reduce the demands made by the environment upon the developmentally disabled person and thus ensure that he can progress more or live longer and better outside the less adaptive mainstream of society.

Though mindful of the argument presented in support of highly specialized facilities and highly specialized interdisciplinary teams, our own experience with severely and profoundly developmentally disabled people persuades me that only in exceptional circumstances and for short periods of time do developmentally disabled people make their most profitable and permanent gains outside the home community and the mainstream of society. However, to achieve lasting progress in the community, we must provide a continuum of services working toward change and improvement in four distinct but interrelated domains. These domains are the following:

1. The condition of the individual.
2. The behavior of the individual.
3. The condition of significant other systems, and
4. The behavior of significant other systems.

This view is represented in Figure 2 on the following page.

Figure 2


Condition of the Individual
Condition of other Systems
Behavior of the Individual
Behavior of other Systems
+ CHANGE = Gains sustained over time

The purpose of intervention in these four domains is to improve the appropriateness and fit among them so that each can more easily adapt to the others.

Condition of the individual: Some improvement in the condition of the individual can be wrought by actions that do not require a substantial change in the behavior of the individual. Here are examples of this:

1. Complete cleaning of the teeth can result in the elimination of offensive odors.
2. Orthopedic procedures can straighten feet or limbs.
3. Addition of glasses and hearing aids can improve sight or hearing.
4. Dressing in well fitting, appropriate, normal clothing, and styling of the hair can create more attractive appearance that dramatically influences relationships and self-concept.

Behavior of the individual: A uniform system of assessing the health and learning needs, pinpointing behavioral milestones in a proper sequence and implementing a process of education and developmental procedures that can be measured with precision will produce increased complexity of behavior and control over the environment. Procedures need to be set up with care and attention, but once established can be maintained by the kinds of parents, teachers, vocational trainers, house parents, and significant others that can be located in most all rural communities.

Changing the condition of significant other systems and settings: We must carefully distinguish between impairment of the individual and disability associated with that impairment. A nonambulatory person approaching a building with steps may be disabled from gaining access. The disability may be eliminated by altering the character of the entrances and exits to the building. Likewise, a person may have an impairment which interferes with ability to control the light in his or her bedroom by flipping the switch on the wall. This disability might be eliminated by altering the way the lights are turned on and off. One can think easily of other examples of how change in the conditions of significant other settings can reduce disability.

Changing the behavior of others who interact or should interact with the impaired individual: The way other systems behave can dramatically enhance or encumber the independence and integration of developmentally disabled people. For example, the behavior of zoning and liscensing personnel, of physicians and

other health care personnel, and of employers can contribute directly to success or lack of success of developmentally disabled people. If a school age student requires medication to control seizures, access to regular classes or special education classes in community schools may be influenced. Where a school has insufficient nurses they may be unable to provide and monitor necessary medical services. However, if the health care system systematically achieves optimum dosage that can be given at times other than school hours, this obstacle to school admission is eliminated. The same method experts use in pinpointing behavior and developing strategies for achieving changed behavior of developmentally disabled students can be generalized to targeting and changing behavior of significant others, be they doctors, policemen, parents, zoning boards, or whomever.

If we grant for the sake of argument, that the foregoing propositions are reasonable we can go a step further. Adding it all up we can borrow from the Tennessee Re-Ed Project, the following view of the situation:

> We assume that each person is an inseparable part of a small social system, of an ecological unit made up of the person, his family, his school, his neighborhood and community. The system may become "Go" as a result of marked improvement in any component, or it may work as a result of modest improvement in all components.
>
> ...The task is to get the individual, family, school and community just above the threshold in the requirement that each component makes of the other component.

If we wish to represent this by a chart, we may find the individual and his world appears either as represented in Figure 3 or Figure 4.

Figure 3

THE INDIVIDUAL AND HIS WORLD BEFORE DEVELOPMENTAL NEEDS MET

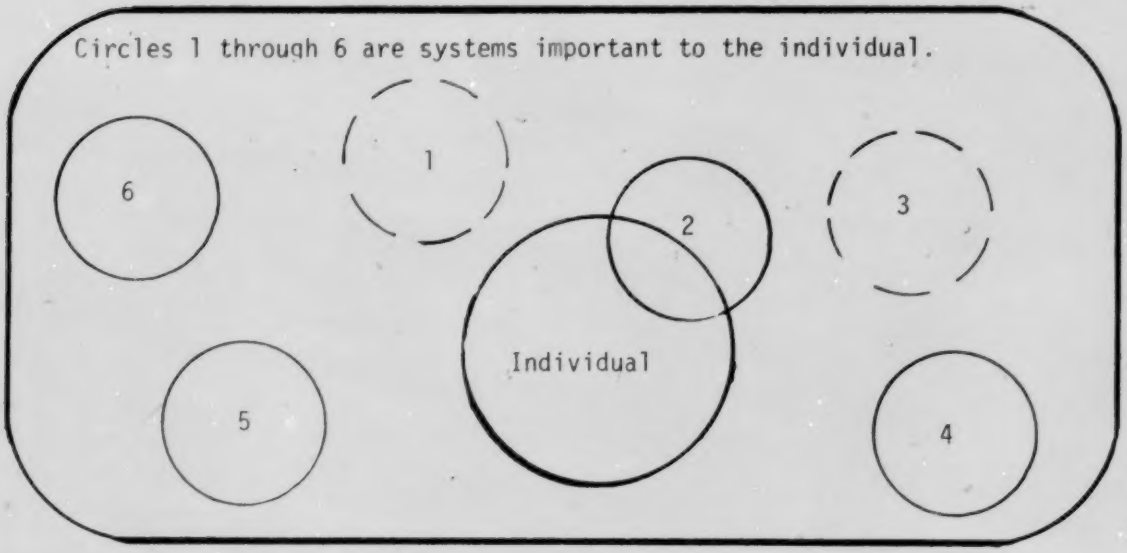
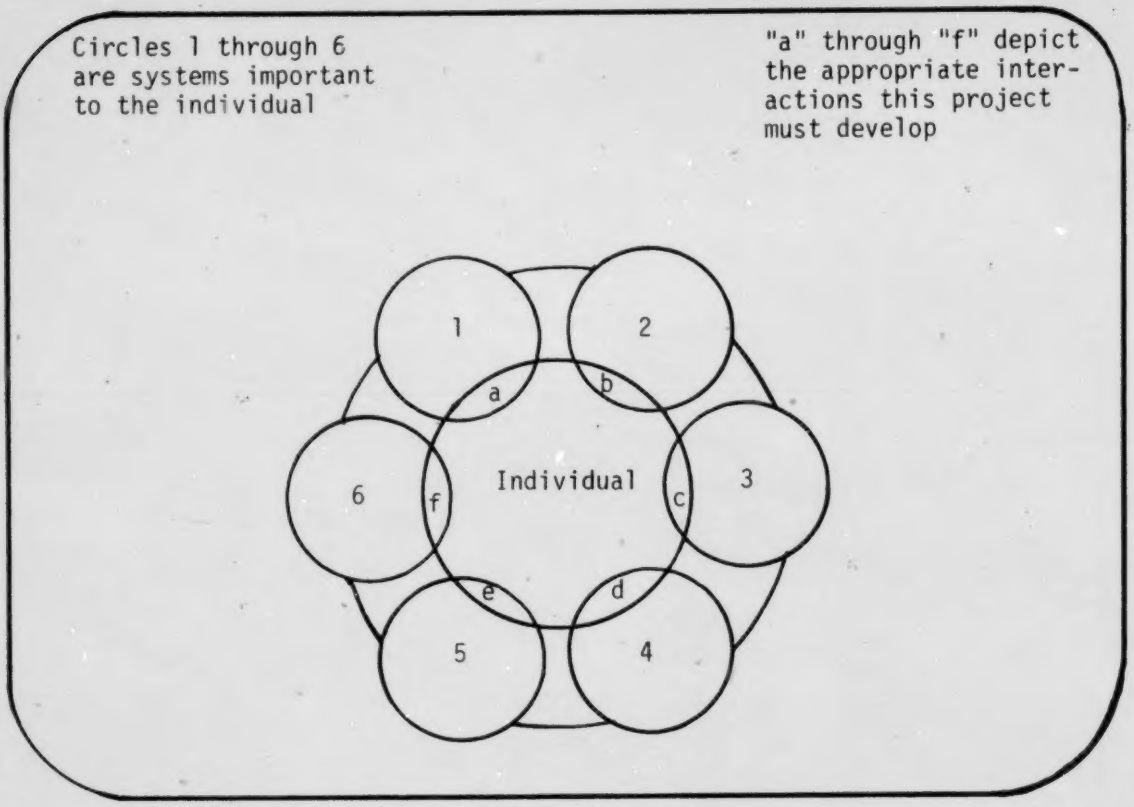


Figure 4

THE INDIVIDUAL AND HIS WORLD AFTER DEVELOPMENTAL GOALS MET

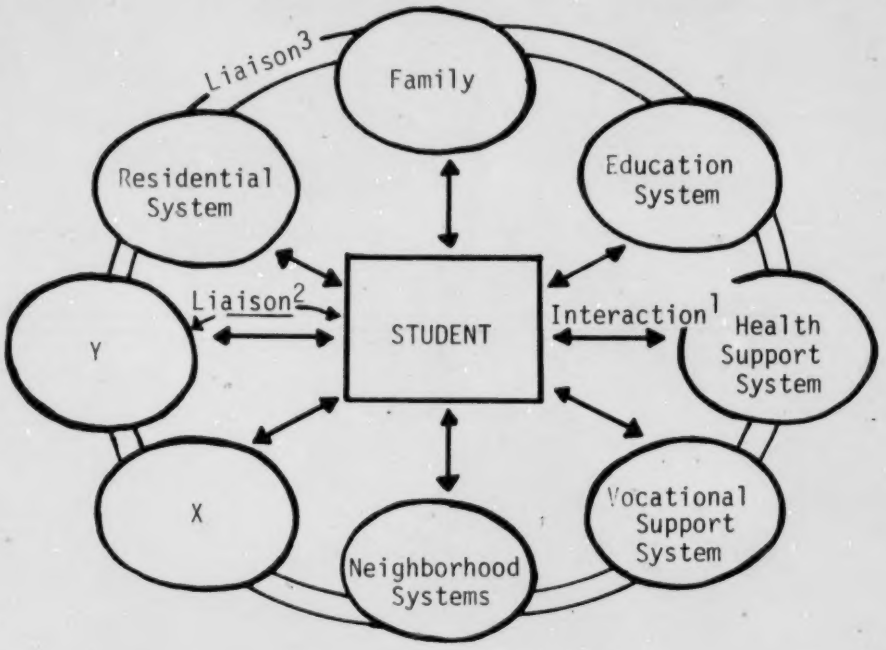


In order to promote effective interaction between the systems it is important to have someone performing what might be called the liaison function. This function can be performed directly by a county agent for families or through volunteers. It is most effectively performed by someone who is not in a chain of command that has direct service responsibilities. The role is schematically depicted by Figure 5.

For each individual in whom you are interested you would place different names in circles one through six of Figure 4. In each case you would list those others who are most significant in the life of the individual. Most likely you would include members of a Key Integrating System and perhaps some from the In Trouble Systems. You would probably include family, residential system and others.

Figure 5

SYSTEM DEVELOPMENT BY LIAISON STAFF



1. Interactions improved by changing behavior of both interactors
2. Liaison function is catalytic - educational
3. Liaison involved in linking systems in logical relationship

In four rural counties in Tennessee an office of County Agents for Children was established.[7] This office was manned by a County Agent, a half-time secretary and volunteers to the County Agent Program. Others saw themselves from time to time as volunteers to specific children or groups of children with special needs. The County Agent Program visualized every person as a member of a social system just as we have described. The task of the County Agent and of those working with her/him was to improve and increase the quality of interaction between the individual and significant others. Also the task was to improve and increase the quality of coordination between the significant others as this affected the individual with needs.

There are some very vital assumptions to this way of viewing the service needs of developmentally disabled people. The most vital assumption is that every community possesses resources that can be better utilized in promoting

the development and success of developmentally disabled people. The challenge is to enhance and improve this latent ability of each community to meet its own needs. This was the attitude of the United States Department of Agriculture that led to the successful establishment of the Agricultural County Agents program. As described in the occupational outlook handbook for the US Department of Labor, the approach of the agricultural agents is this:

> Extension workers help people analyze and solve their farm and home programs. Much of this work is carried on in groups, through meetings, tours, demonstrations and local volunteer leaders. Individual assistance is given on problems that cannot be solved satisfactorily by group methods. Extension workers rely heavily on mass communication media such as newspapers, radio and television... Extension workers must be proficient in both subject matter and teaching methods.

Examination of the history of this program demonstrates that the extension agents effectively have taught farmers to understand the esoteric language of agricultural research and the scientific methods most likely to lead to success in animal and plant husbandry. The lesson is that with equal effort, great strides can be made in similarly improving the capability of those in rural communities to meet the service needs of the developmentally disabled citizens.

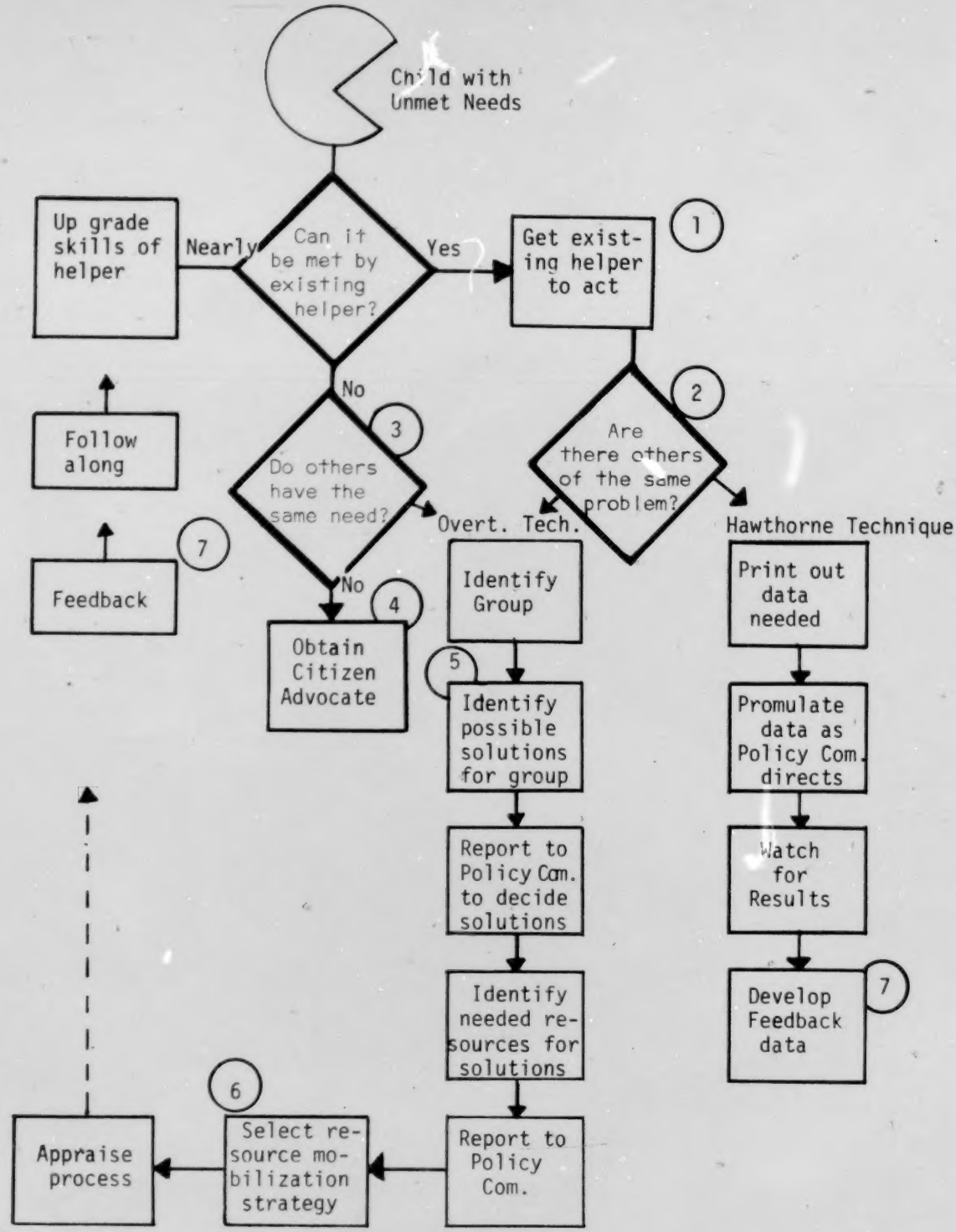
What is being suggested are several new ways of looking at the problem of service delivery in rural settings. Each of these assumes that all the strategies for linking resources to developmentally delayed and impaired people can be carried out in rural settings. I am also suggesting that for the most part, the resources for carrying out these strategies likewise exist in rural settings. The challenge is to properly develop links and utilize them. Viewed in this way the primary manpower deficit is small, but is a very critical one. What is needed is a system that assures proper analysis of need and effective fostering and linking of resources needed to carry out the strategy required to meet those needs.

One of the most effective ways County Agents for Children worked to help communities to meet the unmet needs of children is outlined in the Strategy for Meeting Needs Chart, Figure 6. Through use of a volunteer advisory council, radio talk shows, visits to a wide variety of citizens in the community, participation in civic clubs and church meetings, county agents soon came to be known as people involved in helping the community meet the needs of children. As a result the county agents began to receive reports about children with unmet needs.

When someone reported to the county agent a child with a problem it was usually found that they had thought about a solution for the child and had encountered problems in achieving a solution. An example of this would be the report that Johnny has a learning disability or an inappropriate behavior stemming from an unknown cause, or any one of several things. There may be several approaches to meeting Johnny's need or solving that problem. One approach (and perhaps the most promising one) may be getting Johnny placed in Mrs. Brown's class. If that is what he needs, then there may be a strategy problem of accomplishing placement or what we call the "problem connected with a solution." There's a difference between original problems and solution problems. Focusing on solutions too quickly obscures the basic problem and diverts the helper from discovering better options.

Figure 6

STRATEGY FOR MEETING NEEDS



As soon as the problem or need was defined, the chart we used required us to ask, "Is there someone ready, willing, and able to meet it?" If we could answer this "yes," then it was merely a matter of referral or linking the child with the need to the agency or person ready, willing, and able to meet the need. If the answer to the question, "Is there someone ready, willing, and able to meet it?" was "nearly," then we had to develop a strategy to upgrade the skills or augment the program or alter behavior, policy, or motivation. We then had to assure that there was follow-along and feedback.

If the answer to the question was "no," we asked another question: "Do others have the same needs?" Here we finally went back and looked at the several ways we'd defined the problem. If one of the solutions for a child was a series of trips for services to Jackson or Memphis we might redefine the problem as "The child needs transportation to Jackson." Then we would ask "Are there others who need transportation to Jackson?" If the answer was "yes," then we would seek to identify the group. If we succeeded with that, we would seek to identify two or three possible solutions from our policy board, people in the community, the central office, the literature or whatever. The next step in our decision making chart was to report to the policy committee. In reality, this was sometimes reported to a social service luncheon or discussed with parents or agency personnel or others depending upon the situation. From this, we usually reached a decision on which of the strategies should receive priority effort. Sometimes during this process or immediately thereafter, we began to look for possible resources that would be required to implement the strategy or solution. Next we sought to develop the means for bringing together the needs, strategies, and resources in a need-fulfilling way. Where possible we sought to get others to carry out the process of bringing together the needs, strategies and resources.

As we sought to implement this type of approach, Robert Mager, in his book[8] Analyzing Performance Problems, taught us that every discrepancy between the performance we saw and what we had hoped for from family members, teachers or service agencies was not a training problem. It is true that sometimes training is sorely needed. However, there are obstacles to performance other than skill deficiency. We learned to ask these questions:

1. Is the performance discrepancy important?
2. Is it a skill deficiency?
3. Is the desired performance punishing?
4. Is non-performance rewarding?

The strategies are known and the resources are here. The main task is effective liaison, linkage, coordination and utilization. The primary task is not the creation of new systems or new disciplines. It is primarily a task of clearly defining each job as it relates to people, to data and to things. Once this is done, we decide on promising strategies that utilize the resources in a need-fulfilling relationship. Once the significant elements have been inventoried and named the next step is to look at their makeup, mission and methods so as to determine how each of these will promote or interfere with an effective continuum of services. Here one may discover the need for change, updating or simplification. After these two steps are accomplished, one needs to develop a mechanism for assuring that the interaction between these systems simplifies the delivery of services rather than complicating them. For example,

if Title XX regulations complicate interaction between a respite care center and the school system, this issue needs to be addressed.

In summary, it is suggested that the life of every developmentally disabled person can be enriched in his own community by promoting the complexity of behavior and control over his environment through systematic use of appropriate liaison services such as that utilized by County Agents for Children in Tennessee. Children, youth and adults not subject to horizontal and tranquil living can be injected into a variety of new settings. They can learn to walk, to feed themselves and to talk. Others can learn to work and live in less therapeutic environments. There is enough skill, enough knowledge, and resources to assure that every developmentally disabled citizen in rural areas can move from the more restrictive to the less restrictive environment. They can move the maintenance of life settings to behavior shaping, preacademic, prevocational and vocational settings, from hospitals and immediate care facilities to group homes, to foster homes, to boarding homes, to sheltered apartments. The models exist, as does the knowledge to change the condition and behavior of significant others. The primary task and the resources are in the community. It is hoped that the suggestions made on how to approach the task will lead to fruitful utilization of our manpower in order to accomplish the goals.

Footnotes

1. The Dictionary of Occupational titles states that every job can be described in terms of relationships to people, to data and things. These relationships can be analyzed and described according to the degree of difficulty involved. The method used in the Dictionary of Occupational Titles can be of great benefit whether one is looking at the role of an agency, a residential facility or the many tasks faced by a developmentally disabled person.

2. Brown v Board of Education, 347 U.S. 483.

3. Wolf Wolfensberger, Toward Citizen Advocacy for the Handicapped (A paper presented to the President's Committee on Mental Retardation, Sub-committee on Law and Guardianship) January 1970. See also Parsons and Bales, Family Socialization and Interaction Process, Glencoe, Illinois: Free Press, 1965.

4. The use of the acronyms "KISS, ITS, and ICE" is adapted from a paper by Eli Bower entitled "Prevention of Behavior Disorders in Early Childhood." No other citation is available to the author.

5. See the Standards for Residential Facilities for the Mentally Retarded (Section 1) and Standards for Community Agencies (Section 7) of the Accreditation Council for Facilities for the Mentally Retarded, Joint Commission on Accreditation of Hospitals.

6. "The ultimate aim of the agency is to foster those behaviors that maximize the human qualities of the disabled person, increase the complexity of his behavior, and enhance his ability to cope with his environment." Standard 7.1.2 of the Standards for Community Agencies, op. cit., note 13.

7. Floyd Dennis. Final Report - County Agents for Children, Parts I, II, III (Proj. No. 223553). Nashville: George Peabody College for Teachers, The John F. Kennedy Center for Research on Education and Human Development, March, 1976.

8. Robert Mager. Analyzing Performance Problems, Fearon Publishers.

CHAPTER 5

SOUTHWESTERN NEW MEXICO SERVICES TO HANDICAPPED CHILDREN AND ADULTS, INC.

A Rural Delivery System

by

Barbara Gray

Southwestern New Mexico is very rural by anyone's definition. Development of a comprehensive service delivery program in this area of mountains, where counties have less than one person per square mile, highlights the problems of rural services.

Barbara Gray, Director of Southwestern New Mexico Services to Handicapped Children and Adults, describes a program that has evolved to meet the unique needs of this region. Normalization is applied to the needs of individuals in their own setting and culture, emphasizing the right of handicapped people to have choices.

Where did it all begin . . . what is now a four-county program meeting the needs of developmentally disabled clients from the "cradle to the grave," known state side in New Mexico as Southwestern New Mexico Services to Handicapped Children and Adults, Inc. It began with a meager program housed in a 200 year old officers' recreation hall overlooking Fort Bayard, with one salaried teacher, a few volunteers, and a small group of children, left all too long to stand still while life around them took giant strides forward.

The program as it began was designed primarily to meet the needs of mentally handicapped school aged children in Grant County. Almost daily, however, needs of clients who did not fall into this narrow category were observed. As such needs were made more evident in Grant County, the scene was repeated simultaneously state wide. In 1966, in order to have a more comprehensive program and to begin some form of state wide planning, the state of New Mexico was divided into eight Planning Districts. Of these, District V was developed to include and enlarge the existing Southwestern New Mexico Services to Handicapped Children and Adults, Inc. (SWSH) programs, expanding the one county area to four counties and the program primarily for mentally handicapped to include all developmentally disabled individuals.

The whole of District V, though comprised of four counties, is primarily rural. Catron county, the largest county in New Mexico in land area, has a population of 2,198 (1970 census), or .3 persons per square mile. It has only two incorporated communities, Reserve and Quemado. Grant county has two open pit copper mines and contains a total population of 23,700; more than one-half of the total population is within the city limits of the county seat, Silver City. Luna and Hidalgo counties border on Mexico and have total populations of 8,343 and 4,755, respectively. Deming, the seat of Hidalgo county, was established because of the railroad. The ruralness, the distances, the mountain roads can all influence, and, at times, dictate the nature of programs.

Southwestern New Mexico Services to Handicapped Children and Adults, Inc. houses under her umbrella nine programs for providing a non-profit, systematic continuum of services to the developmentally disabled. SWSH provides the mechanics for a tailor-made program, which humanely and economically meets the unique needs of every developmentally disabled person and his family.

The purpose of providing these services was so that no developmentally disabled person would have to leave the community for such services. The agreement under which SWSH was created emphasized the intention to create, in district, administration services which are not or cannot be provided by other agencies for handicapped citizens. Therefore, it was developed, not as a public entity, but as an agency designated to "fill the gap" between existing services.

The administrative structure consists of two board members from each county and one board member at large. This board comprises the governing body which maintains complete authority concerning all SWSH transactions. Served in the nine program areas are individuals of all ages and disabilities. It is important to note that all individuals and on-going planning activities and service efforts are the result of the combined efforts of parent/professional involvement. In formulating specific needs, citizen groups in each area of southwestern New Mexico meet and plan together for a program to meet

the needs of their area. From these initial meetings, the program grew.

The Cholla Day Care Program in Grant county, has between nine and fifteen severely and profoundly, physically and mentally handicapped clients. The staff consists of a Director/Teacher, Teacher Aide and a part-time Aide and provides services typical of a certified day care program. Training to each child's ability, physical and speech therapy, adaptive behavior, occupational therapy, along with parent counseling, all constitute the full day, five days a week, twelve months a year services. The program's purpose is to offer relief to parents, to prevent institutionalization, and is operated on the belief that some growth is possible for all handicapped.

The Ocotillo Preschool, Grant county, serves twenty to twenty-five preschool aged developmentally disabled clients. The purpose, in addition to day care, is to provide functional education including social skills and family counseling. The staff consists of Director/Teacher, Associate Teacher, Teacher Aide and general Aide; it maintains a 9:00am to 4:00pm schedule, and attempts to prepare capable students for regular public education programs. Non-handicapped students of preschool age have been included and the resulting social integration has been shown to be beneficial to both the handicapped and non-handicapped.

El Paisano Preschool and Day Care in Luna County, meets the needs of nine developmentally disabled individuals, age five to twenty-five, including profoundly retarded, trainable mentally retarded and clients with communicative disorders. The staff consists of a full time Director/Teacher, Teacher Aide and volunteer. A 9:00am to 2:00pm, five days a week, twelve month program is followed. This program is designed to offer services through stimulation activities for those persons excluded from state supported educational and recreational programs, in an effort to educate, train and, where feasible, prevent school failure. Also included in the program is parent counseling, speech and physical therapy and successful integration in social activities.

Yucca Center, Hidalgo county, is housed in Lordsburg and meets the same needs of the developmentally disabled as the other preschool and day care facilities. However, due to the sparse population of this area, the program must meet the individual needs from infancy to adulthood for clients who range from mild to profound in their handicaps. This staff consists of a Director/Teacher certified in special education, and a para-professional Aide who maintain a 9:00am to 4:00pm program, year-round. Plans are being made to include an adult homebound program for leisure time activities. Presently, many developmentally disabled persons live on farms and ranches in the area and have already achieved a purposeful life by assisting their families with domestic and field tasks. These people do not have need of most of the services offered at the Yucca Center. However, a leisure time program for socialization would be of enormous benefit to these citizens.

Two Rehabilitation Centers, one in Luna county and one in Grant county, serve forty to fifty-five physically and mentally handicapped adults through testing and evaluation, vocational training and planning, daily social, personal and work adjustment group classes, job placement and follow-up, sheltered employment, adult education, physical and speech therapy, and recreational programs. Staffing these programs are a Coordinator of Rehabil-

itation Centers, Evaluators, Instructors, a Woodwork Foreman, Shop Foreman and a Secretary. Both programs maintain an 8:30am to 4:00pm yearly schedule. They attempt to provide clients with work, social experiences and exposure to community living. This plan has proven successful in that many clients go from institutions into full time jobs as taxpayers.

The New Mexico Native Plant Nursery, Grant county, utilizes one of the state's largest natural resources, its National Forest. A staff consisting of a Supervisor and Assistant Supervisor maintain the same work day schedule throughout the year in operating a native plant nursery and providing landscaping services while training ten developmentally disabled individuals plus public school work study trainees. The services to clients in this project include horticulture, carpentry and janitorial training, social and self adjustment skills, recreation and work with the community on landscaping contracts. This project receives technical advice from Resources, Conservation and Development Services, Home Extension Service of Grant County, and Plant Material Center of Soil Conservation Service at Los Lunas, New Mexico. One of the newer contracts served by this project is with the Gila National Forest for clean up and maintenance services of several public use areas. Clients sign a contract with the project for part of the work, becoming a partner, often for the first time in a legally documented job.

Due to the rural nature of District V, three residential centers, two for men and one for women, are included in the SWSH umbrella. These homes are maintained with the goal of independent living. Clients are provided the services of home counselors, instructors and business advisors, yet always strive for independence on the part of those clients who are capable. From 1973 to 1976, eight adults have moved to independent living, three to semi-independent living, and two have been admitted to a short term institutional program.

Last, but not least, possibly the most innovative of the SWSH programs is the "School on Wheels" serving Catron county which has a .3 person per square mile population. Here, in 1974, the anguish of a Catron countian was expressed, . . . "Services have been denied Catron county because of her vast size and small population. We have virtually been told we do not have the same privileges as other citizens of the state because we are rural. Do we have to have factory pollution and people pollution to have our children made straight and strong again? It's true that any program such as this must budget half its funds for mileage. Hamlets average 60 miles apart, and in wet weather are up to two hours drive apart. The problem for Catron county is as it always has been - too few, too far, to matter."

With this and other expressions of the need in Catron county and with their cooperative efforts, a program was planned and initiated. In the fall of 1975, Title III funding and a dedicated staff made it possible for special education services to be made available to Catron county's exceptional children. A qualified, enthusiastic staff was hired and a Winnebago Motor Home was transformed into a motorized learning center.

The "School on Wheels" staff and Supportive Team of Southwestern New Mexico Services to Handicapped Children and Adults, Inc. met with the school personnel to explain the purposes and goals of the program. The classroom

teachers referred students who were having academic and/or behavioral problems. The parents of these students were contacted by SWSH and a Social Worker explained the program. From approximately 97 referrals, 92 parents gave their consent for testing. After the tests and educational evaluations were completed, the results and recommendations for appropriate placement were made to teachers, parents and students.

The Supportive Team was composed of a Speech and Hearing Pathologist, Physical Therapist, School Counselor/Psychologist, Special Education Teacher and Social Worker. Their task was to gather pertinent data and administer appropriate tests in the following areas: communication skills, self concepts and physical activity. Individual prescription plans were written for each student and scheduled with the classroom teacher and "School on Wheels" staff. The staff of the "School on Wheels" and the Supportive Team feels that significant progress has been made based on subjective evaluations, performances, and objective progress tests and attitude changes.

Included in all programs is the flexibility of respite care and homebound services when the need arises. Short term respite care in residential units when there is a vacancy and/or placement in foster homes in a district facility for the handicapped have proven an asset to the SWSH programs at many times these are needed on an emergency basis. Homebound services are provided by a Social Worker, Counselor, Occupational Therapist, and Physical Therapist to clients and families.

Recreational programs include evening recreation for adults, summer recreation and a Special Olympics program. The May through August summer programs include swimming, camping, crafts and sports, evening hours for adults (year round), socialization activities and regular physical recreation activities as part of the daily program. Staffing this program is a physical education teacher, student teachers from Western New Mexico University, senior student teachers in local high schools, and the SWSH staff. An interesting outgrowth of this program was the completion of the motorized trail for handicapped in the Gila National Forest, enabling non-ambulatory handicapped to visit scenic and recreational areas. The recreational programs integrate students of public schools special education classes and the non-handicapped in many activities.

The Transportation Program is one strength of the total SWSH program. It is made possible through the cooperative efforts of the County Commissioners in each of the four counties, the Division of Vocational Rehabilitation, Developmental Disabilities and the New Mexico State Highway Department. Clients are transported to and from training facilities, job placements and passenger specially equipped bus and two 12-passenger vans in Grant County, two 16-passenger vans in Luna county, and one 12-passenger van in Hidalgo county. Staffing this Transportation Program is a Chief of Transportation and five state qualified drivers, two of whom serve as maintenance and repair men, also. Unfortunately, lack of vehicles causes some clients to be in transit for as long as one hour. However, through this program, 100 to 190 clients are transported daily to available services which would not otherwise be feasible without the Transportation Program.

Support Services in Southwestern New Mexico Services to Handicapped

Children and Adults, Inc., through diagnosis and evaluation, include a continuing identification program for District V. Here, as elsewhere, previously unknown handicapped individuals are identified by parents, teachers, social workers or physicians who bring or refer the problem to one of the community programs. SWSH employs a diagnostic and treatment team which includes a Speech Therapist, a Physical Therapist and an Occupational Therapist who work with a Family Social Worker/Counselor. Due to lack of funding, it is necessary to have one support team which serves all counties in District V. This team travels throughout the district, counsels with families of handicapped children and arranges for indicated tests and referrals for medical services. The purpose is to obtain a complete assessment of the handicapped individual, as the basis for placing him in the best program to meet his needs, whether a SWSH program or a service offered by another agency.

The SWSH Administrative Office maintains a data center on all persons in the SWSH program and provides information and referral services as part of the data center. The data is kept current on the basis of reports from the directors of direct services programs and the support services staff. In cooperation with Western New Mexico University, a computer information system on clients in the district is being planned. This system will be useful for updating prescribed programs for clients and providing information for the Health and Social Services Department to determine eligibility of clients for services on the basis of disability and income.

Counseling and social services are offered in the district. A staff of three full time employees, a Family Social Worker/Counselor, a Social Worker, and a Social Worker Aide is responsible for contacts with families and health and welfare offices. They consult regularly with the program directors on the individual prescribed program for each client.

Specialized therapy at SWSH includes physical, speech and occupational therapists who serve clients in all direct service programs. Public schools and head start programs may contract for consultant services. Physical therapy services must be prescribed by a physician. These include general exercises, gait training and ambulation, balance and coordination exercises. The New Mexico Elks Cerebral Palsy Unit provides additional physical therapist consultation as requested on special problems. Severe speech and hearing problems are referred to the Speech and Hearing Center at New Mexico State University, Las Cruces, New Mexico.

SWSH has not yet been able to fund comprehensive district-wide medical and preventive services. Limited medical services are available through private providers and the public health services. Some clients are referred to specialists in El Paso, Texas and Las Cruces, New Mexico. Neurological problems are referred to Socorro Neurology Unit, Socorro, New Mexico. Orthopedic needs are referred to Carrie Tingley Hospital, Truth or Consequences, New Mexico and Health and Social Services Department's Crippled Children's Services. Certain services are offered through the local health office.

There are on-going staff training programs with the training of volunteers as office, teacher and recreational aides. Carrie Tingley Hospital a state facility for crippled children, is developing a workshop to train para-professionals in physical rehabilitation. Speech aides are trained

in special workshops by the Speech Pathologist of SWSH. SWSH also cooperates with Western New Mexico University in training teachers for special education. Local associations such as the Association for Retarded Citizens (ARC) pay professional educational consultants to conduct seminars for the staff of SWSH. The seminars are on such topics as sex education for the retarded and behavior modification. The Department of Vocational Rehabilitation has also rendered invaluable services in the area of staff development and professional growth.

An asset to the SWSH programs is the cooperation of community resources. Many of these have been mentioned. However, one that deserves more than just mention is the Association for Retarded Citizens. These affiliated memberships in each of the four county areas have often times been the strength, support, and challenge SWSH needed in order to foster a program. The ARC's have been sympathetic to the intent of promoting the welfare of handicapped children and adults and have been steadfast in their support of and safeguarding of the rights and interests of handicapped persons. As the handicapped are frequently impaired or disadvantaged in such a way or to such a degree that they cannot adequately represent their interests as a group in society, the Associations perform a group advocacy function on behalf of handicapped persons through their input into the community through local government. The Associations act to eliminate cases of social problems affecting handicapped citizens through public education and information techniques and by soliciting support from civic groups and concerned citizens to work toward the resolutions of social and legal barriers to services for and acceptance of handicapped persons. They are the fixed points for collecting and disseminating information and also provide a citizens' review of all SWSH programs within their county. This review includes assessment of SWSH policies, program objectives, facilities and budgeting.

In summary, the philosophy of the SWSH program concerning normalization explains why, in spite of seemingly insurmountable problems, the effort is well worth it. SWSH feels that the meaning of normalization is the right of every person to live in the least restricted environment. One often is found thinking that "normal" is to do what the majority do, e.g. live in the city; however, what SWSH defines as "normal" is what is normal for a given region. As many people choose to live in the country, on a ranch, the handicapped should have this choice. Some single adults choose to live at home, while others may choose to live in apartments or communities; the handicapped should have this choice, as well.

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CHAPTER 6

CLIENT IDENTIFICATION:
IDAHO CHILD FIND AND PUBLIC AWARENESS

by

Linda Gibbs

Locating and identifying all persons eligible for and in need of services is a major issue confronting service providers. Idaho state law mandates a free public education for all handicapped children, and Idaho has developed a successful Child Find effort to make sure that all children receive that education.

In this chapter, Linda Gibbs, Regional Resource Consultant at the College of Education, University of Idaho at Moscow, describes a process for identifying all handicapped children. The process is designed to operate in a rural area and below cost by maximizing the use of volunteers.

Introduction

All children in Idaho are entitled to a free, public education. The Idaho compulsory attendance law applies to children ages 7 to 15. Furthermore, the Idaho Code, mandates that school districts must provide education and training for all resident exceptional pupils, defined as:

> children whose handicaps, or whose capabilities, are so great as to require special education and special services in order to develop to their fullest capacity. This definition includes but does not limit itself to those children who are physically handicapped, mentally retarded, emotionally disturbed, chronically ill or who have perceptual impairment as well as those children who are so academically talented that they need special education programs to achieve their fullest potential.

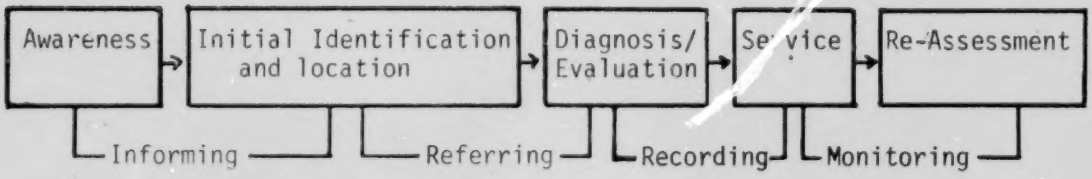
In addition, federal legislation (PL 93-380) requires that state departments of education develop plans to identify, evaluate and diagnose all handicapped children in order to receive federal funding for special education programs. On November 28, 1975, President Ford signed the Education for All Handicapped Children Act (PL 94-142) which increased the federal role in stimulating states to provide full, appropriate programs for handicapped children. The intent of PL 94-142 is to provide a free appropriate public education for all handicapped children between the ages of 3 and 18 by 1978, and to all handicapped children between the ages of 3 and 21 by 1980. In response to the state and federal legislation, the following step by step plan was developed by Dr. Judy Schrag, Director of Special Education, to insure that Idaho would have an ongoing and comprehensive statewide Child Find system.

Idaho Child Find Identification Components

The Idaho Child Find Identification model consists of the following components:

Figure 1

Full Services Model



In developing the Idaho Child Find system, it was believed essential that all aspects of the full services model be considered. Since child identification is but one component of the provision of full and appropriate service, planning for all components of the model must be done simultaneously. Included

below are some of the objectives under each component of the model which have been identified by Dr. Schrag to insure that all handicapped children in Idaho would receive full and appropriate services:

A. Awareness

1. To release information through television, radio, and newspaper media by State Department of Education, regional Child Development Centers, United Cerebral Palsy, Idaho Epilepsy League, Idaho Association for Retarded Citizens, etc. regarding early childhood development and Idaho services for children whose development differs from expected milestones.

2. To disseminate information packets and multimedia presentations by United Cerebral Palsy of Idaho, Inc. and Idaho Epilepsy League.

3. To establish local task force groups--7 regions were identified in Idaho.

4. To distribute posters, information sheets, bank statement stuffers, information booklets.

5. To disseminate the booklet "How to Obtain Special Education Services for Your Child" by League of Women Voters and the Mental Health Association to parents of handicapped children and professionals working with handicapped children.

6. To disseminate parent letters with mail return identification forms to identify unserved handicapped children. The letters will be sent home with all Idaho school children in selected grades.

7. Speakers and taped messages will be available to civic and social organizations.

8. A 15-minute slide tape presentation, "Idaho Child Find," will be scheduled for use by PTA groups.

9. To distribute a series of pamphlets entitled "Growing Up in Idaho" to parents of first born children by the Department of Health and Welfare. The purpose of such pamphlets is to inform parents of the milestones of normal child development, the needs of young, growing children, and the resources available for meeting these needs.

B. Initial Identification and Location

1. To assist with kindergarten-first grade screening within local school districts.

2. To assist with the Early Periodic Screening Programs to be carried out by District Health Departments and regional Child Development Centers.

3. To assist with screening for vision and hearing problems conducted by Child Health Services.

4. To disseminate "Growing Up in Idaho" pamphlets to assist parents in the screening of their child's development by providing information regarding average developmental milestones.

5. To institute letters being sent by local school districts to parents with a screening developmental scale to assist parents in screening young children as well as older out-of-school children for possible handicaps and/or developmental lags.

C. Diagnosis/Evaluation

Idaho State Rules and Regulations for Special Education require that no child shall be enrolled in a special education program unless he has received a comprehensive evaluation.

Although the extent of such a comprehensive evaluation shall depend on the nature and the severity of the handicapping condition, it is a multi-disciplined assessment which takes into account the physical health and condition of the child, psychological assets and liabilities, communication skills, social adjustment and adaptivity, educational achievement, and the assessed intellectual level of each child.

Idaho State Rules and Regulations also specify that diagnosis/evaluation must utilize a multi-disciplinary team approach in the evaluation of handicapped children. Thus the State Department of Education will:

1. Provide assistance to local school districts in diagnosis/evaluation of handicapped children by State and Regional special education consultant services.

2. Provide assistance to local school districts in diagnosis/evaluation of handicapped children by Regional Child Development Centers and the North Idaho Panhandle Child Development Association.

3. Provide assistance and support to local school districts and other agencies for comprehensive evaluation of handicapped children through the Northwest Regional Resource Center Title VI-B, and state funds.

4. Provide a special study on comprehensive evaluation utilizing Northwest Regional Resource Center and state resources by Idaho school psychologists and directors of special education in order to appropriately modify state Rules and Regulations and to develop best practices.

5. Through contractural agreements between the State Department of Education and the Idaho Department of Health and Welfare the screening services available to preschool children between the ages of 0 and 4, will be expanded.

D. Educational Service Delivery

Preschool Handicapped Children

1. Through contractual agreements with early childhood service providers, the State Department of Education extended the continuum of state special services to handicapped children of preschool ages 0-4.

2. To provide technical assistance and support by the North Idaho Panhandle Child Development Association in order to train teachers and parents working with identified preschool handicapped children, as well as to establish standard pupil assessment procedures.

3. To provide technical assistance and support by the Portage Project, Northwest Area Learning Resource Center, Northwest Regional Center, etc.

School Age Handicapped Children

1. To assist Special Education Programs (classroom and homebased) within local school districts, contractual agencies and organizations, Idaho State School for the Retarded, Idaho State School for the Deaf and the Blind, etc., utilizing state, regional, NWALRC/RRC and federal Title VI-B resources.

2. To provide technical assistance and support by State Department of Education state and regional consultant services.

3. To provide support from Title VI-D and the North Idaho Panhandle Child Development Association for inservice training of special education personnel serving identified handicapped children.

4. To provide special Title VI-G project to develop best practices in programming for unserved learning disabled children.

Special Studies to be initiated by the State Department of Education

Further refinement of competencies needed by education personnel, appropriate certification changes, transportation problems of handicapped children, and investigation of factors affecting high turnover of special education personnel in Idaho.

E. Re-Assessment

Funds

Idaho State Rules and Regulations for Special Education require that local school districts and contractual agencies provide an annual review of all handicapped children, and that the Selection and Placement Committees must provide continuous review of the child's progress within the placement setting.

The remainder of this chapter constitutes a summary of the planning principles used in Idaho to design and implement the Child Find component of the Full Services Model.

Some Child Find Planning Principles

The immediate purpose of Child Find is to secure as complete a list as possible of all handicapped preschool and school-age children who are out of school or not participating in any education program. Names of school-age handicapped children are submitted to appropriate local school district personnel; names of preschool handicapped children are submitted to regional Child Development Centers, other appropriate community programs, or the State Department of Education. The long-term goals are to establish in Idaho a process for ready entrance into a system of free public programs of education and training appropriate to meet individual developmental needs of all school-age children, as well as to provide young handicapped children access to early education programs.

The following principles were considered in designing Idaho's Child Find system:

1. Determine the parameters of the public information campaign such as: a) fiscal barriers, b) geographic barriers, c) personnel barriers, d) legislative barriers, e) informational/communication barriers, f) social barriers, etc. To assess the situation, first examine the federal regulations and guidelines, then examine state statutes that may affect what can and cannot be done. Some states, such as Idaho, have legal exclusion of "disruptive" children from regular classrooms or from the whole school. Some regulations governing the activities of state agencies are also obstructive - e.g., the available fiscal resources and the administrative responsibility for a given task may reside in two different agencies.

2. Within the existing parameters, develop a simple but systematic plan which will include all action steps to be taken during the public information campaign. The plan should include:

    a. all of the action steps that will be needed
    b. how long these will take
    c. who will be responsible for each step

3. Negotiate agreements or contracts with any and all available service agencies to provide at least partial back-up services in areas with limited capability. In Idaho, for example, another system was needed to help preschool children because of unavailable state funds. As several private agencies were already helping young children in various ways, Idaho's special education director established an inter-agency contract to expand this service.

4. Whenever possible, join with other service delivery systems (via agreements, contracts, etc.) to extend the capability for child identification, location and referral. Again, examine the federal regulations and guidelines, as well as state statutes. Some agencies on the state and local level are already working with the handicapped, thus it is important to identify what are their priorities, legal responsibilities, resources, etc. Would they be willing to cooperate in carrying out Child Find activities? In Idaho the League of Women Voters was already developing a booklet for parents of handicapped children entitled, "How to Gain Access to Special Education Programs." The State Department of Education assisted in the printing and dissemination of this booklet.

5. Locate and utilize or adapt existing media and materials for public information campaigns - this will save both time and dollars to insure an integrated awareness campaign statewide. Design the public information campaign to insure saturation at the community level.

6 . Mobilize volunteer task forces on the local level to systematically carry out Child Find Activities. With the support of the state organization of the League of Women Voters in Idaho, seven regional coordinators were recruited from their membership to help plan and initiate Child Find activities in each of the seven regions of the state. A one-day training workshop was held on September 26, 1975, to acquaint the volunteers with project procedures and activities to be conducted during the month of October. At this time the coordinators were given sixteen major objectives that they were asked to carry out during the month of October as well as all materials (speech material, posters, brochures, etc.) that would be needed.

The State Department of Education in Idaho decided to initiate Idaho's Child Find efforts and to provide an intensive month long search in October of 1975 to provide maximum support of identification and location of handicapped children. A mass-media campaign was carried out during October in a joint effort by the State Department of Education, Idaho Department of Health and Welfare, the Idaho Association for Retarded Citizens, Child Development Centers, Governor's Advisory Council on Developmental Disabilities, Idaho TORCH, public and private agencies, and parent and civic community groups. All efforts have continued on an ongoing basis after the October campaign. Such ongoing efforts include:

1. Bank stuffers were delivered to participating Idaho banks to be included in the November bank statements to their customers throughout the community.

2. Stuffers in church bulletins during November.

3. Letters explaining Project Child Find were sent home with all first through fifth grade students in the state of Idaho during the month of February.

4. A slide-tape presentation explaining Project Child Find was prepared for presentation to PTA organizations in the state of Idaho during the months of March and April.

Summary

Idaho is a rural state where a small population is scattered over a large geographic area. The work of the League of Woman Voters made it possible to spend most of Idaho's limited funds on materials and yet reach audiences over the entire state. The League volunteers stated that the Child Find effort has been one of the most effective state projects by providing communication and cooperation between the State Department of Education, the regional consultants, volunteer organizations, parents, agency personnel, etc. The regional coordinators felt that there had been excellent support for their efforts at all levels, (State Department of Education, regional and local). The coordinators also stressed that their local credibility was maintained throughout the project as the provisions necessary to deliver educational services to children

identified through Child Find were initiated by the appropriate agency immediately. In conclusion, the Idaho State Department of Education found that actual communication by staff personnel and local volunteers with groups and individuals was one of the most effective vehicles utilized in Idaho Child Find to identify unserved, handicapped children.

Hopefully, this summary of Idaho's planning principles, objectives and activities will be of help to other planners.

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Supplement 1

Idaho's Sixteen Objectives and Activities

The seven coordinators were asked to meet with the regional special education consultant of the State Department of Education who was to provide them with any assistance that they might need in carrying out the identified objectives. The following are the sixteen objectives and their related activities that the volunteer regional coordinators were asked to carry out during the month of October:

1. Contact any local TORCH (State High School Organization) volunteers who have responded to the State Department. Names will be given to you.

   Activities:

   a. Each regional coordinator received a list of TORCH members who had volunteered to give an identified amount of time to help carry out Child Find activities.

   b. The coordinator contacted the TORCH members in their region and gave them assigned activities to be carried out at a given date. (Activities included distributing brochures, posters, fliers, etc.)

2. Identify other volunteers who could assist with Child/Public Awareness activities, (in your own town and neighboring towns).

3. Assign various tasks to identified volunteers.

   Activities:

   a. Prepare a schedule for volunteers. (Determine when volunteers are to carry out scheduled tasks).

   b. Give volunteers specific tasks. (Where they are to go, what types of information they are to disseminate, etc.)

   c. Provide volunteers with any needed materials, sample letters, sample TV and radio releases, etc. (see Supplement 3 for sample used).

   d. Any press releases, posters, etc., should emphasize both local and state phone numbers.

   e. Ask volunteers to let you know if they need any assistance and to also let you know when they have completed the assigned activities.

4. Make or arrange for a personal visit to local television stations regarding Child Find public service spots.

   Activities:

   a. Make available to regional coordinators a copy of all TV stations in their area.

   b. Provide sample releases to radio stations.

   c. Have the regional coordinator arrange a local interview to discuss Child Find in Idaho.

   d. Have coordinators check to see if TV spots are being played during prime time.

   e. Send a letter to TV stations thanking them for supporting Child Find.

5. Contact radio stations regarding Child Find announcements.

   Activities:

   a. Make available to regional coordinators a copy of all radio stations in their area.

   b. Provide sample radio spots.

   c. Have coordinators check to see if radio spots are being played during prime time.

   d. Have the regional coordinator arrange a local interview to discuss Child Find.

6. Contact legislators, State Board of Education members, agencies serving handicapped children and ask for newspaper releases in support of Idaho Project Child Find.

7. Call your designated regional school superintendent; identify yourself; leave your phone number and encourage calls or information requests. (The state organization of Superintendents had been asked at their state meeting to identify a superintendent in each of the seven regions who would be responsible for disseminating information to other superintendents in the region).

8. When regional doctors are named, the State Department will communicate with you. Please call and introduce yourself to this doctor; leave your phone number and encourage calls regarding transfer of names to the State Department of Education. (The state organization of the American Medical Association was asked at its state meeting by Dr. Judy Schrag, Director of Special Education, to support Child Find Activities and to identify a doctor in each region who could be contacted regarding Child Find Activities.

9. Contact and work with your regional special education consultant who will be providing assistance in your region.

   Suggested activities for regional consultants:

   a. Assist regional coordinators in obtaining materials. (tapes, posters, brochures, etc.)

   b. Make contacts with radio and television stations.

   c. Give talks to local civic and business groups. (A prepared tape explaining Child Find will assist any volunteer in presenting talks to local, civic and business groups).

   d. Assist coordinators in administrative activities:

      i. Prepare any needed duplicated materials (letters, tapes, etc.)

      ii. Prepare any reports for regional coordinators of activities as requested by the State Department of Education.

      iii. Assist regional coordinator in finding volunteers in any rural towns when the coordinator has been unable to find assistance in distributing Child Find materials.

      iv. Act as a liaison between regional coordinators and the state department.

      v. Organize any regional meetings for coordinators.

      vi. Assist coordinators in preparing a time line of all identified activities.

      vii. Support the coordinators - be available to assist in any way possible to carry out their activities. Periodically call the regional coordinators to see if any assistance is needed.

10. Make or arrange for contact with all local civic and business groups.

    Activities:

    a. Develop a list of suggested community resources.

    b. Chamber of Commerce will provide local list of civic and business groups.

    c. Make a list of community resources and identify who will be responsible for contacting each group with Child Find information.

    d. Provide cassette tape explaining Child Find that may be used at civic and business groups' meetings.

11. Contact PTA presidents and ask them to have the October meeting support Idaho Project Child Find. (Including distribution of posters, etc.)

12. Contact or arrange for contacts with church groups, ministers, priests, etc., for announcements regarding Idaho Project Child Find, local canvassing, distribution of materials, etc.

13. Ask regional special education consultants to solicit from the Council for Exceptional Children.

    a. Distribute materials to areas identified by regional coordinators.

    b. Assist in mailing out materials to areas identified by regional coordinators.

    c. Assist in making contacts with University radio and TV stations.

    d. Prepare news releases to the campus newspaper.

    e. Make or arrange contacts with all groups on campus to explain Child Find in Idaho.

    f. Assist with any follow-up activities as identified by regional consultant and regional coordinators.

14. Respond to local, regional concerns and calls, or refer calls accordingly.

15. Mail any registration forms which identify handicapped children who are out of school or unserved to the proper referral source.

16. Attend meeting at the end of October to plan ongoing activities throughout the school year.

Supplement 2

Updated Child Find Radio Announcements

(for use until Nov. 15)

30 seconds

Idaho's Project Child Find is working! A number of handicapped children have been found and served through school programs or community services. If you know of a handicapped child who is not in school or receiving help, write

Project Child Find
State Department of Education
Boise, Idaho 83720

or call

384-2203

* * *

10 seconds

Idaho's Project Child Find is working! School programs and community services are available for handicapped children. If you know of a handicapped child who is not in school or receiving help

call

384-2203

Supplement 3

Child Find Television Announcement

Script: Videospot #1

Setting: Child between ages 10-18 months appears on lap of adult who describes normal development of children in this age group; plain background; child is handling a play object.

Most children between 10 and 18 months can crawl, walk and climb. Some can go up stairs by putting one foot, then the other on the same step. They learn by listening, feeling, pushing, pulling, upsetting, biting or tasting. By 18 months, most children can run and like to be chased. They understand many words and can name familiar things, like "dog" or "horse." Words are beginning to form sentences, like "Me do it."

Not all children develop in usual ways, however. Some are handicapped. Special help is available for these children and their parents. If you know of a young handicapped child, please write or call your regional Child Development Center or Project Child Find.

CHAPTER 7

TRIP

A Comprehensive Transportation Plan for West Virginia

by

Roy E. Payton

Transportation is one of the most frequently mentioned obstacles to serving the developmentally disabled in rural areas. A West Virginia program that has been designed to provide transportation for low-income aged and handicapped people is known by the acronym TRIP.

The TRIP program which uses both fare vouchers for existing transportation and specialized transportation is described in this chapter by Roy [illegible] Payton, Assistant Commissioner of TRIP.

Introduction

This chapter describes the purpose, philosophy, and intent of TRIP, the Transportation Remuneration Incentive Program. TRIP is funded by four Federal agencies through the West Virginia Department of Welfare. The purpose is to provide bus transportation service in areas without any type of public transportation and to supplement existing transit systems with feeder and additional service routes. TRIP was conceived in 1973 primarily by those groups who desired a low-cost method of transportation for low-income, aged, and disabled populations.

TRIP consists of two phases. The subsidized ticket fare system was the first phase, and was implemented in June, 1974. The second phase of TRIP is the actual transit system that consists of different types and sizes of buses, tailored to meet the service implementation schedules within eleven regional entities in West Virginia. The transit system phase also includes two special demonstration projects, the PostBus and Health Transporter. These two demonstrations will provide special transit needs as identified in the Transportation Development Plan for West Virginia.

Demographic and Geographical Data of West Virginia

The entire state of West Virginia is the target location of the TRIP Program. The 1970 census shows that 61% of West Virginia's approximate population of 1.8 million live in rural areas while only 12.7% live in central cities. Sixty percent of the State's 55 counties are 75% rural, and only 15 counties have population densities greater than 100 persons per square mile.

More significantly, however, is the situation existing for those individuals for whom the TRIP subsidized fare ticket system was designed. The more rural counties in West Virginia have a larger percentage of their population aged 60 and over. The number of automobiles per capita in these rural counties is less than 80% of the national average. Fifty-seven percent of West Virginians in this age group reside in rural communities of populations under 2,500, and there is a disproportionately high statewide growth rate of 1.2% annually in the population segment of 60 years or older. Finally, there are approximately 150,000 handicapped or disabled West Virginians or nearly 10% of the State's total population. These individuals are limited in travel by geography, and the problem is compounded by the rural and mountainous terrain within the State, making access to basic service centers difficult and costly.

Subsidized Fare Ticket System

The subsidized fare ticket system (TRIP tickets) began in June, 1974. Tickets are issued to those aged and disabled applicants who meet the eligibility requirements of the program. A $4 million grant from the Community Services Administration is providing the funding for the three year demonstration period 1974-1977.

The TRIP ticket functions in a manner similar to that of the Food Stamp Program. A TRIP ticket book consists of 32 coupons valued at 25¢ each. This ticket book, valued at $8, can be purchased by an eligible recipient at a discount ranging from $1 to $5, depending on household income. The tickets can be used on any type of transportation approved by the Public Service Commission of West Virginia and properly registered with the TRIP Program.

One of the primary reasons that the West Virginia Department of Welfare was selected to implement TRIP tickets was because this agency has an intimate knowledge of the target group and has local offices located in each of the State's 55 counties through which to take applications and issue the tickets. Generic clerical personnel experienced with Food Stamp issuance are utilized throughout these local offices to issue TRIP tickets. Workers within the Eligibility Unit perform the task of taking applications and making periodic eligibility redeterminations of TRIP cases as well as all eligibility-related tasks for public assistance and other programs within the Department of Welfare.

Eligibility Requirements

One must be (1) at least 60 years of age or physically and/or mentally disabled and (2) meet the household income and resource guidelines to be eligible for TRIP tickets. Table 1 shows the income, asset and ticket issuance schedule. TRIP costs and ticket values were established by surveying the travel characteristics of potential TRIP users. Next, the round-trip cost factor of different travel modes utilized by potential TRIP users was determined. Then an estimate of the total number of TRIP users throughout the three year demonstration period was determined. These three factors were combined to determine the best possible subsidy rates, within budgetary limitations.

With the use of the centralized TRIP data system consisting of computer terminals located in each local welfare office, most applications can be processed daily, and the applicant may receive his tickets on the date of application provided he meets the eligibility requirements. Although the eligibility guidelines based on household income and resources are determined through use of a simple graduated scale, the severity of the applicant's disability is also considered. If the existence of the applicant's disability is questioned, medical documentation is requested. The majority of disabled applicants are already known to the Department of Welfare and medical documentation typically exists for the eligibility requirements of other programs. For example, disabled children receiving services under the Crippled Children's Program in West Virginia would be automatically eligible under the disability criteria of the TRIP Program. Similarly eligible are disabled persons receiving benefits from Vocational Rehabilitation, Workmen's Compensation, Black Lung or other programs designed to assist disabled persons. If necessary, however, home visits are made to verify eligibility.

Trip Tickets

An individual may use his TRIP tickets for whatever purpose he chooses.

Table 1

Transportation Remuneration Incentive Program

Eligibility Requirements

MONTHLY ALLOWABLE INCOME STANDARDS AND BASIS FOR TICKET BOOK ISSUANCE:

Number of Eligible Persons	Non-Farm Family (Individual)		Farm Family (Individual)	
	Yearly	Monthly	Yearly	Monthly
1	$3,036	$255	$2,580	$215
2	3,996	333	3,408	284
3	4,956	413	4,212	351
4	5,916	493	5,028	419
5	6,864	572	5,844	487
6	7,824	652	6,672	556
7	8,724	727	7,500	625
Each Additional Member Add	900	75	770	64

Farm households will mean persons living on places of ten or more acres from which sales of farm products amounted to $50 or more in the preceding calendar year or on places of less than ten acres from which sales of farm products amounted to $250 or more in the preceding year.

Table 2

TICKET COST AND VALUE:

Allowable Monthly Income of Eligible Individuals	One Person		Two Persons		Three or More	
	Ticket Cost	Ticket Value	Ticket Cost	Ticket Value	Ticket Cost	Ticket Value
$ 0-255	$1.00	$8.00	$2.00	$16.00	$3.00	$24.00
256-333			4.00	16.00	6.00	24.00
334-413					9.00	24.00
414-493					12.00	24.00
494-572					15.00	24.00
573-652					15.00	24.00
653-727					15.00	24.00

This may include visiting friends and relatives, traveling to entertainment centers and shopping for goods and services. TRIP tickets can only be used for traveling in vehicles that have satisfied all public carrier requirements of the West Virginia Public Service Commission. In addition, these carriers must be properly registered with TRIP by substantiating that they have met the requirements of the Commission. TRIP tickets may be used for out-of-State travel provided the fares are paid for in West Virginia on providers such as Greyhound, Trailways, or AMTRAK.

Each approved participant is allowed one TRIP ticket book per month except qualified special hardship cases which may receive up to a maximum of three books per month. Hardship is based on remoteness of location or the need for numerous visits to a clinic or physician. Each participant receives an identification and authorization card to prevent unauthorized persons from purchasing TRIP tickets. When fares are paid by the participant, he simply removes the required amount of tickets from the book and drops them into the fare box for payment of service.

TRIP and the Developmentally Disabled

As a special service to assist the severely and/or developmentally disabled, an authorized attendant may be allowed to travel with a TRIP participant. Special provisions allow this attendant to utilize TRIP tickets for his travel expenses. This attendant may also purchase TRIP tickets for the participant to prevent hardships in obtaining the tickets. The intent of this policy is to encourage mobility so that the developmentally disabled may participate as fully as possible in normal activity enjoyed by those who are not severely handicapped. TRIP allows the aged and disabled the all-important social function of selection and participation.

Another special provision of TRIP allows participants to have essential items such as medicine and groceries delivered to their home via taxi. Without making the actual trip, the participant may pay for this delivery service with TRIP tickets. This service is provided to those participants who need this convenience on an emergency basis or if because of illness or disability, they are unable to travel.

The foremost disadvantage of rural-based participants when compared with urban-based participants in regard to the TRIP ticket phase is that of higher overall transportation costs. The following discussion of the TRIP transit system or the second phase of the TRIP Program will illustrate how this transportation-cost gap will be narrowed.

TRIP Transportation System

Phase two of the TRIP Program, the TRIP Transportation System, supports and complements the program goals of the TRIP ticket component. The major program goal of the TRIP Transit System is to transport anyone who wishes to ride and pay the required fare while the ticket component is categorically related to groups.

The Transportation Development Program for West Virginia outlines for each of the eleven regions in the State a transit system composed of TRIP and existing transit systems as conceived and operated by local transit authorities. The eleven regional entitities within West Virginia known as Regional Planning and Development Councils are empowered by State law with the authority and political structure to establish transportation authorities. TRIP transportation specialists work very closely with the appropriate administrative staff in these regions as they finalize the transit development plan for each region. After the development plan is approved by TRIP and the Regional Council, a contract is drawn up between these two parties for the receipt and disbursement of operating subsidies for one year of operation. At the present time, contracts have been finalized in two of the eleven State regions. Implementation will begin in these two regions after the transit authorities complete their preparation. TRIP receives funds from the Urban Mass Transportation Administration and the Federal Highway Administration of the Department of Transportation to pay for capital equipment, operational subsidies, transportation planning, transportation demonstration and administrative costs incurred in the implementation of the regional TRIP transportation systems.

TRIP Bus Design

A total of 215 buses is planned for the statewide TRIP transportation system. Below is a brief summary of each type of bus:

1. Primary Midibus (primary route): This bus has a 20 passenger seating capacity, 20.2' in length, 8' in width and has a curb weight of 8,000 lbs.

2. Primary Minibus (primary and feeder routes): This bus has a 12 passenger seating capacity, 20' in length, 8' in width and has a curb weight of 7,000 lbs.

3. Primary Van/Minibus with Wheelchair Capacity (feeder routes): Each region will receive two wheelchair buses with the exception of Region IX which will receive one. It has a capacity to seat 12 passengers and adequate space to accommodate three wheelchairs during movement. It is 20' in length and 8' in width and has a curb weight of 7,000 lbs. It is equipped with a wheelchair hoist and platform. The hoist and platform is hydraulic-powered and operates the platform from street to vehicle floor in 10-20 seconds.

Special Demonstration Project: The Health Transporter

In an attempt to meet the special transportation needs of West Virginia and cope with the mountainous rural locale, the TRIP Transportation Plan

includes two special demonstration projects to effectively meet these special transit needs.

The Health Transporter proposes to improve access to specialized health services, reduce patient absenteeism from prearranged appointments, reduce dependency on transport designated for emergency use (ambulances, etc.), and integrate with other transportation services.

The primary function of the demonstration is to provide long distance transportation to specialist medical facilities on a coordinated appointment basis for outlying regions. The major features of the operational profile of the Health Transporter will be high average speeds with few stops and travel time of up to two hours one way. Most of this travel will be on primary roads or divided highways up to and including interstate routes. Over-the-road travel conditions will, therefore, predominate in vehicle selection with priority given to stability, steering and braking capability as well as riding quality and safety. An additional consideration would be for adequate turning ability in confined entrances at medical facilities.

It is to be expected that passengers will in many cases have some ambulatory restrictions or sensory problems, therefore, primary emphasis must be placed on ease of exit or entry and onboard comfort and security. Provisions must also be made for carrying paraplegic and quadraplegic patients and for storing their wheelchairs for the journey, which may be quite lengthy.

Since the primary purpose of the vehicle would be long distance travel for medical appointments, speed and comfort are primary considerations. The air conditioned vehicle can maintain a high average speed of 40 mph. The vehicle would be an eight door stretched automobile similar to the type commonly used in airport limousine service. Seating consists of individual highback bucket seats for the maximum comfort of seven passengers. It is 22.5' in length, 7.6' in width and has a curb weight of 5,300 lbs.

In this demonstration, service will be available only to those with health related appointments and the patients will be taken to the medical facilities and returned to their points of origin. The vehicle is designed to handle a wide variety of patient types provided, of course, they are able to ride long distances. Patient ridership is identified as non-emergency and non-contagious cases and the vehicle can accommodate a stretcher patient and attendant. The travel routes essentially flow from rural areas into the appropriate medical service centers on a long-distance basis. The operation and purchase of the Health Transporter vehicle will be financed through the Urban Mass Transportation Administration and the Administration on Aging (Department of Health, Education and Welfare).

Special Demonstration Project: The PostBus

One of the alternatives identified by the TRIP Development Plan is the PostBus which combines mail and people delivery in the same vehicle. The idea is not entirely new as variations exist in foreign countries (particularly Scotland) and in very isolated circumstances in the United States. However,

as a coordinated method of transportation within a region, the idea is innovative especially in view of American travel habits, patterns and needs as well as the United States Postal Service's requirements. By combining two previously separate services into one, the allocated costs for each service would almost be halved resulting in a transit service being provided at minimal cost. PostBus adds additional meaning to the phrase "resource integration." The Postal Service serves almost every road and accesses almost every household with mail delivery. As such, it is already supporting a service financially either by having employees delivering mail in Postal Service vehicles or by contracting the service to an individual or company with a private vehicle. By "piggybacking" or adding a new service to an existing service without burdening either, the transit service can utilize an existing driver and supplant a mail or private vehicle with a bus and operate over the postal routes according to the Postal Service's schedule. Costs of providing mail service are already underwritten by the Postal Service which means that operating costs are zero; an incentive fee could be paid to the driver for being a bus driver and maintaining the vehicle while the fee can be a set amount, payable from fares collected. The only other major costs are capital which, if a public agency is operating the service, can be financed by United States Department of Transportation Capital Grant Programs. By integrating the resources, the two services can be provided at the cost of one.

A major overriding consideration is where PostBus service can be provided. PostBus is essentially a low-density transit service providing a very basic service. Particular guidelines have yet to be established. Therefore, it is necessary to evaluate each situation individually in view of what type of service is desired and what realistically can be provided in light of various constraints. Although it is the intent of the demonstration project to develop and define criteria for the types of services PostBus can provide, certain generalizations can be made:

a. An ideal situation would provide a trip to a local activity center (town, village, etc.) with a reasonable layover time and return trip. However, even one-way trips are beneficial.

b. The routes should serve a "rural" population density so that riders can travel somewhere; the service should not become bogged down with mail deliveries at close intervals throughout the day.

c. Route selection should be based on not duplicating other existing transit services and on accessing a potentially responsive population.

TRIP Management/Information System

The management/information system, including both manual and computerized procedures, covers two major areas: the system dealing with the transportation user and the system dealing with the provider of this transportation.

The potential user of transportation under TRIP makes an application which is accepted when the requirements for eligibility are met and the information is verified. Information about the applicant and reconciliation of the authorization cards are both handled by remote telecommunications terminals in the area offices. Monthly computer listings include information on active households. Audit information includes listings, both monthly and annually, on all tickets sold to every household. Lists of households that have been inactive for over fourteen months and households whose eligibility has to be redetermined are furnished to the local offices. In addition, these offices and the Department are furnished statistical information on denied cases, household data including needs for transportation, and time spent by the worker.

The potential provider of transportation applies for authorization to accept TRIP tickets and, once approved, is entered on the computer files. Providers then periodically turn in their collected tickets for cash reimbursement and this is recorded in the computer files. Periodic and cumulative audit reports of financial data are produced, including lists of financial activity by provider. Statistical information is produced on the activity of TRIP-provided vehicles and the total activity of the provider.

Summary

The overall goal of the TRIP Transportation System is to provide statewide lower-cost transportation for all who desire and need the service. In order to achieve this goal, the TRIP system was carefully and closely interfaced with existing public carriers in order to offer maximum service with the least amount of duplication. TRIP buses were designed not only to meet the rugged demands of the mountainous routes but also to meet the special needs of the aged and developmentally disabled. TRIP buses will serve primarily as feeder vehicles in urban areas such as Charleston, West Virginia, where urban mass transit is well developed. In rural areas TRIP buses will serve both as primary and feeder route vehicles.

Much has been written during the last decade regarding the complex socio-economic and psychological human needs of our Nation and society. During recent years, however, with environmental concerns and shortage of fossil fuels adding to the critical nature of the problem, transportation has entered a new dimension. It has become expensive for those who can afford to divert more of the household income to this rising cost but prohibitively expensive for the aged and handicapped who cannot afford the rising costs of mobility. While the aged encounter economic problems with generally fixed incomes, the disabled must contend with much higher overall living expenses because of special needs and loss of earning ability.

The United States is the most mobile society in the world. If one in our society is to have the goods and services that he needs, he must have a high level of mobility to obtain them. Nowhere in our Nation has this problem become more acute than in rural or low-density areas and no one in our Nation is more negatively affected than the aged and disabled who reside in these areas. The problem for this group is two-fold: the non-existence of public transportation and the rising cost of taxis and private automobiles.

If this group is to enjoy a dignified life in this society, they must have a sufficient mobility to participate in and select options from the society in which they live.

The two-phased nature of the TRIP Program seeks to accomplish the goal of providing mobility to the aged and developmentally disabled by drawing upon the vast resources of revenue-generating fares from the general public to make the transit system a self-supporting transportation service for all.

CHAPTER 8

HI-LINE HOME TRAINING

An Approach to Home Training and Respite Care for the Developmentally Disabled in Rural Montana

by

Susie Hubbard

One approach to serving the developmentally disabled in very rural areas is to bring services to the home. An example of home training and respite care in rural eastern Montana is Hi-Line Home Training, Inc.

In this chapter, Susie Hubbard, former staff director of the Montana DD Council, points out the advantages and difficulties of this approach and outlines the day in the life of a home trainer in eastern Montana.

A Day in the Life Of A Home Trainer

The day starts early for the home trainer. Before 8:00 a.m., she leaves the motel where she stays each week in a small town of 800. It will be a long day during which she will see five developmentally disabled people. She usually tries to limit herself to four a day, but because it is a busy season for farm families, she must adjust to their schedules.

The drive to the home of the first family, mostly on a dirt road, takes over an hour. The road is dry today, but the trainer remembers the time her car slid off the road into the muddy ditch and she had to walk four miles to the nearest farm for help in the cold and rain with only sandles and no jacket. Now she always carries sturdy walking shoes and a warm sweater. This first family includes Ken, a Down's Syndrome child, age four, his mother and father, grandmother and three siblings. As expected, the father is out working when she arrives, but the others are expecting the home trainer. The mother has the previous week's progress charts completed and ready to discuss. Ken is learning to match colors and say simple words. Four months ago, he had no intelligible speech. Now he says his name and many words, although, his articulation is poor. Several weeks ago he spoke his first spontaneous phrase. The trainer has brought some new color matching cards plus a tape of her voice telling a story with words for Ken to repeat as he looks at the series of pictures. The session continues as Ken is helped with a balancing exercise by his sister.

The trainer records progress on the last week exercises and obtains a base level performance on the new assignments. She and the mother go over some of the new assignments with Ken. As the trainer watches this healthy active youngster, she recalls that his doctor did not refer him to the home training project, because he felt that "since Ken was a Mongoloid, he was a hopeless case and would die soon anyway."

The next visit is over an hour away from Ken's and again the road is a dirt one and very dusty. At first she used to wash her car regularly, now it is rarely clean. A stop at the local gas station elicits friendly hellos and small talk. The gas station owner knows her well and has helped to fix flat tires and assist in other vehicle emergencies.

Carla and her mother are glad to see the trainer. She was at a special camp last week and is anxious to show the candle and moccasins she made there. Carla, age twenty-three, had never attended special education classes or received any services before the home training was initiated four months ago. Carla is mentally retarded, partially blind and has cerebral palsy. She can not walk but does crawl around the house. Through the trainer's arrangements, Carla had a physical therapy evaluation two months ago and with the help of her mother, she is now involved in a daily therapy program. The physical therapist, who will see Carla every three months, thinks she may walk some day. Although Carla's mother had taught her most of the necessary self-help skills, she had not attempted any kind of academic or pre-vocational programs. Now with the trainer's help, Carla is learning letters and number concepts. After a home visit, the trainer often drives Carla to the work activity center in the nearest town, about sixty miles away. Eventually, Carla may move to the new group home there and attend the program regularly. In the meantime, the

progress at home is encouraging to Carla, her family and the trainer.

The third visit is to a nursing home patient. Like Carla, she is twenty three, retarded and has severe cerebral palsy. Unlike Carla, Kathy has resided at the state institution and at nursing homes for most of her life. The nursing home is clean and pleasant, but the aides and nurses are busy and have no time to carry out individualized educational programs. With some reluctance on the part of the nursing home, the home trainer was able to arrange for an aide to conduct a daily physical therapy program with Kathy. Another of Kathy's primary needs is speech therapy. Speech therapy is hard to come by in this area, but the trainer has managed to get a speech evaluation and has recruited a volunteer, with a bachelors degree in speech, to come in several times a week to work with Kathy. The trainer finds a note from the volunteer that says Kathy worked hard last week and is making some progress. The trainer shows Kathy a new form board she has brought and attempts to interest her in trying to record her speech. Kathy is tired today and the lesson results are discouraging. The trainer leaves a note for the volunteer and some new picture cards.

Before the fourth visit, she stops in for a quick lunch and to exchange some material with the program supervisor at the work activity center. Again, it requires a long, hot drive to get to the fourth family. This foster family has had fourteen year old Mary with them for only three weeks. Mary, who is severely retarded and epileptic, had been living in the state institution until this family provided her with a home. Home training services are short term here since Mary will soon enter a residential school program. In the meantime, the mother has requested help in teaching Mary to speak and to follow direction. Since Mary is asleep, the foster mother and trainer go over her progress and work out the assignments for the next week.

It is almost four o'clock and the last visit is over one and a half hours away, but it is one of her favorite homes to visit. The foster family has had Pete for 2 months now and the changes have been remarkable. Pete is a 4 year old Indian boy who has suffered severe deprivation since birth. At age two, he was found in the trunk of a car. It has taken about two years to get him settled in a stable foster home. Pete has little speech but he is now making many sounds, thanks to the continued help of the foster brothers and sisters. All four of them work with him and are enthusiastic and proud of his progress. The foster mother and oldest daughter have been through the respite care training and are also willing to provide both in home and out of home respite care services. The trainer originally brought Pete to them as a temporary respite placement between foster homes but the family became so attached to him that they arranged to keep him permanently. The family is busy and very active and had difficulty keeping program records. The assignment paper usually gets lost during the week although the actual assignments do not. The trainer has several new toys that make animal sounds which Pete is learning to imitate and exchanges them for other toys she has brought in the weeks before this visit.

At 7:00 p.m., she heads for home. It is a long 2 1/2 hour drive to her house. After a quick stop for dinner, she is on the road again. As it gets dark, she notes that she can drive miles in this area without seeing a lighted farmhouse in any direction. She remembers how different her conception of living in a rural area was before she moved here. Upon returning home, she

goes through the last few days mail and new supplies which have come to the office located downstairs in her house. She brings her log up to date and makes a few notes to prepare for the next day. It has been a long day and she has traveled 315 miles.

Community Based Services for the Developmentally Disabled and Region I

In order to understand how the home training program just described came into being, it will be helpful to review a series of events that have taken place since the Spring of 1975.

State Legislation: In April 1975, the Montana Legislature approved and funded the Developmental Disabilities Act for Community Based Services. This act provides for the development of community services to prevent institutionalization and to serve developmentally disabled persons in communities throughout the state.

> 71-2405 - Community Services - The department may establish and administer community comprehensive services, programs, clinics or other facilities throughout the state for the purpose of aiding in the prevention, diagnosis, amelioration or treatment of developmental disabilities. Programs, clinics, or other services may be provided directly by state agencies, or indirectly through contract or co-operative arrangements with other agencies of government, regional or local, private or public agencies, private professional persons or in accredited health or long-term care facilities.

The act also mandated the State and Regional Developmental Disabilities Advisory Councils. Prior to 1975, Montana had a State Advisory Council but efforts to organize regional councils had been fragmented and short lived. Under this new act, regional councils were established to review and evaluate needs within the region, advise the operating agency (Department of Social and Rehabilitation Services) and develop a regional plan for community based services. The boundaries of the Regions were set up to conform to the Governor's planning regions.

Region I: This region is made up of 17 counties in eastern Montana and covers an area of approximately 56,000 square miles or roughly one third of the entire state. The region is distinguishable not only by its vast land area and low population density, but also by the uniqueness of the residents. The people of Region I are ruggedly individualistic, fiercely proud of eastern Montana and eager to point out their special characteristics and needs. In entering Region I, the visitor is struck by the lack of snow capped peaks and abundant forests. However, native eastern Montanans are quick to point out that mountains make them nervous as they like to see where they have been the previous day and where they are going to be the next.

In 1975, the total population figure for Region I was 93,221. This figure may have increased slightly as Region I has recently experienced a population growth due to rich coal deposits and mining activities (particularly Colstrip). Even with the increase in mining, agriculture remains the major industry of the area.

Using the 3% national figure to compute the estimated number of developmentally disabled individuals, it would appear that Region I has approximately 2,8000 developmentally disabled citizens. However, this figure is probably misleading and far from substantiated. At this time, 228 children are being served in special education programs in eastern Montana. An additional 36 children attend the program at Eastmont, a small state institution for developmentally disabled children, which is located in Glendive, Montana. Slightly over 100 adults and children are currently receiving specialized services for the developmentally disabled in activity centers, sheltered workshops, group homes, and home training programs. Some of these people and others are also receiving services under the adult protective services programs of county social services offices. A small undetermined number of developmentally disabled persons are being served by county health nurses and mental health centers. There are several reasons for the potentially large number of unserved developmentally disabled individuals in Region I. First of all, specialized services for developmentally disabled children and adults are new to eastern Montana. As of June 1975, there was only one sheltered workshop program in operation serving approximately 34 adults. Less than a year ago, there were no group homes, no work activity centers, and no home training programs. Special Education classes have also been started only recently in most districts. In 1974, the legislature passed a mandatory education act but set the final implementation date for 1979. Because of relatively few special education students in small districts, local schools have been slow to develop special education programs and have continued to look to Eastmont for services for mildly and moderately handicapped students (Eastmont can only serve a fraction of these referrals). It would appear that many families have already left eastern Montana and moved to Billings, Bismarck or other population centers seeking services for a developmentally disabled family member.

Region I Developmental Disabilities Council: This Council was officially convened in late spring of 1975. Representatives and alternates were elected from the 17 counties. Most of the Council members are parents or relatives of developmentally disabled people (17 out of 20 members). Others are special education teachers, mental health workers, and interested persons. The Council is staffed by the Regional Developmental Disabilities Specialist employed by the Department of Social and Rehabilitation Services.

In September 1975, the Council prepared its first regional plan and set forth a number of broad goals as well as establishing a philosophical basis for services in Region I. The plan stated that all programs developed should be consistent with human and legal rights and should allow for maximum development of the individuals served. In addition, the Region I plan stressed maximum resource usage and economical efficiency. Included in the list of services planned for Region I was this statement related to home training programs:

> We intend to develop home training programs which will serve eastern Montana children, or foster children etc., who are developmentally disabled and are in need of specific and structured home training programs. To this end, we are currently exploring the possibilities of Portage and Monmouth, particularly through the on-going functioning of the Glendive ARC. We further recognize the need for mobile home trainers who have the capability

of serving all residents of eastern Montana. These needs will be addressed by the development of such programs in Miles City and Malta and by supplementing Glendive's program.

To actually carry out this plan for home training, 3 small model programs were designed. The Regional Council then submitted grant applications for the three projects to the State Council and received funding for all three. The three programs were established with different service delivery mechanisms designed to serve specific geographic areas of the region. The Regional Council then planned to evaluate the models in June of 1976 after six months of funding. It was hoped that the evaluation would provide some grounds for decision making in the development of the 1977 regional plan.

The first model was established to serve parents of developmentally disabled pre-school children in a home setting in Custer and surrounding counties. The home trainer was set up as a staff member of the sheltered workshop program in Miles City. The second model was based in Glendive under the auspices of the Southeastern Montana Association for Retarded Citizens and again provided home training services for pre-school youngsters. However, the training was to be provided by a team of volunteers including a special education teacher, a social worker, a foster mother, and one additional person. The third model established an itinerant respite provider and parent trainer who was to develop both services in a five county area in northeastern Montana.

The remainder of this chapter will describe the third model, Hi-Line Programs. It is important to look at the demographic and service information for the five county area and the original program concept designed to serve the area. Experience with the clientele, training tools, costs, and service delivery problems have helped to shape subsequent changes in the program and have led to plans for the future.

The Hi-Line is a five county area in Northeastern Montana with approximately 36,000 residents. The largest town is Glasgow which has a population of approximately 4,700. Other large towns include Plentywood (2,381), Malta (2,195), Wolf Point (3,095), Poplar (1,289) and Scobey (1,486). The majority of people in this area live on farms or in towns of 300 or less. The major industry is farming. The area also includes the Fort Peck Indian Reservation, one of the largest reservation areas in Montana. Almost 7,000 persons in the Hi-Line area are classified below the poverty level. The majority of these low income people are native Americans living on the reservation.

As there are only 13 doctors to serve the entire area, medical care is extremely limited. Public Health Nursing services are also limited and nurse caseloads are very high. There are 6 small rural hospitals and one larger one in Glasgow. One of the small hospitals is operated by Indian Health Services and serves the reservation Indians. There are very few resources for speech and physical therapy. The only speech therapists available are employed by the larger school districts. There is only one physical therapist located in the Hi-Line area.

Social service and education resources are increasing but are still scarce. Each of the 5 counties does provide social services through one or more county social workers. Mental Health workers are located in Glasgow and Plentywood.

There are new specialized service programs for developmentally disabled adults including group homes and day activity centers in Glasgow, Malta, and Plentywood. Special education programs are offered in most of the districts including two TMR classes in Nashua.

The home training and respite care program first began in February, 1975, under the sponsorship of the Malta Association for Retarded Citizens. The Association agreed to act as the non-profit Board of Directors for the program until other arrangements could be made. In June 1975, a new board was formed and incorporated as Hi-Line Home Programs.

The original concept for the home training and respite care program called for an itinerant trainer who would provide in-home respite care for families of developmentally disabled children and adults as well as set up individualized training programs where needed. In addition, follow up home visits to assist and train families could then be scheduled. Over the past seven months, the program has evolved and changed into the current service delivery system. Additional changes are now being planned to better meet the needs of developmentally disabled people in this section of Montana.

Shortly after the Malta ARC Board agreed to sponsor the program, they hired the home trainer. Out of a group of qualified applicants, they chose Sue Rose to fill this position. Although she had little experience in home training or services for the developmentally disabled, she had other important experiences and qualities to offer. She had a Masters degree in Human Communication and experience in evaluating and organizing services in a rural area.

The first month of the project was devoted to staff training. Sue attended training for four days in Portage, Wisconsin and then spent two weeks with a very experienced and knowledgeable parent trainer, Kathleen Gallacher, in Missoula, Montana. She also received training from two teachers of severely handicapped children while in Missoula. Most of her education for this job had to come from reading and consulting with individuals who had had experience with developmentally disabled people.

Upon her return to the Hi-Line, Sue was faced with the need to determine the target population, develop a public awareness program and compile a resource list before she could actually begin to offer and provide services. Therefore, she spent the second month carrying out these activities.

The Regional Council felt confident that many individuals in northeastern Montana could profit from the home training and respite care services but no actual case finding had been done. Sue contacted not only schools, ARC groups, social workers, and other professionals but also newspapers, churches, and local clubs. She then sent information sheets to the families whose names she received from all sources and followed up with a phone call and visit to the family. The major referral source was, and still is, the Regional Council members who live in the area. These members have frequently contacted the families of developmentally disabled children and adults that they know or have heard of. Sue also began work on her resource file. She read everything available, met with every professional person in the area, and put together extensive resource information for her own use and for that of other people working with the developmentally disabled.

By April, Sue had three families involved in home training on a regular basis and was also doing respite care periodically. Already, she began to encounter problems in being both the respite provider and home trainer. First of all, those in need of respite care wanted it provided outside of their home and Sue had no way to supply it herself. She was occasionally able to utilize a friend's house to provide relief for a foster mother with two developmentally disabled four year olds, but this was not a real solution. Secondly, she found that some rural families were not as receptive to the idea of respite care as had previously been envisioned. Many have extended families who assist in times of need and other families are hesitant to take their family member to unknown persons. Few rural families take "vacations." Thirdly, she found that providing respite care sometimes conflicted with pre-arranged home training appointments.

In a report prepared in early July, Sue reported her client load as follows:

Home Training Month	Number of Clients Served	Number of Contacts
April	3 clients	6 contacts
May	9 clients	18
June	14 clients	42
July	14 clients	42 (projected)
Respite Care		
May	1 client	3 whole days
June	5	6 whole days & 4 half days
July	3 (projected)	5 whole days (projected)

In early May, Sue developed a plan for respite care utilizing volunteers. Over the next few months, she recruited 15 volunteer respite providers and then through the Montana Developmental Disabilities Training Institute, the volunteers received two days of extensive training in respite care services. These trained volunteers, under Sue's direction, are now capable of meeting the respite care needs of the area. The volunteers cover a wide geographic area and can provide both in and out-of-home care. The providers include a mature 16 year old girl, several senior citizens, farm families, social service homemakers, etc.

As Sue began to receive referrals for home training from regional Council members, doctors, social workers, friends, and others, she scheduled one or more home visits for assessment and evaluation for each referral. In the evaluation process, Sue administers the Denver Developmental Screening test or Alpern-Boll for a rough evaluation and uses the Portage Guide to Early Education check list and/or Behavior Development Survey for a more comprehensive evaluation. Sue had chosen these evaluation tools because of her training in Missoula and at the Portage Project in Wisconsin with the recognition that she may wish to use others as she increases her own evaluative capability. Sue attempts to assess the current level of development in the areas of cognition, self-help, socialization, communication and motor skills. After the evaluation, she must then

examine attitudes and feelings about home training with the families and the developmentally disabled individuals. If agreeable, an individual program is developed, including both long and short term goals. Wherever possible and needed, Sue has attempted to get speech and physical therapy evaluations and follow up home programs. She generally visits each home weekly, although, some families are served on a two week schedule.

As may be seen, Sue serves not only a large geographical area but also a wide age and disability range. According to her understanding, the program was designed to serve developmentally disabled people of all ages who are in need of specialized home training and/or respite care. It is interesting to note that the youngest child served in the program is 3 years old. Sue had hoped to serve more infants and toddlers but has found that local doctors and others do not generally identify or diagnose babies and very young children as developmentally disabled (unless they make referrals to the institution at birth). More often than not, parents are told that the child "will outgrow it." This summer, Sue has worked with families whose children are home for 3 months and will return to residential programs the rest of the year. Two other children listed are also tentatively scheduled to enter the residential program at Eastmont in September. Recruitment for developmentally disabled people needing services is no longer necessary as referrals are coming in much faster than anticipated and Sue already has a waiting list of 20 families. She is trying to provide evaluations for these families as the referral comes to her but time limitations are making the provision of even minimum services impossible. Since April, she has closed only one case because the mother did not have sufficient time or interest to follow through on the programs. Although not included in the current list, Sue keeps in contact with two additional families who she feels could profit from home training but are still resistant. She is currently encouraging them to use the respite care program.

The costs of this project have remained relatively low. A State Council grant of $3,000 covered the initial training costs (including the trip to Portage, Wisconsin) and teaching materials.

The purchase of service contract through the Developmental Disabilities Division of SRS for the period of March through June 1976 was for $7,100 to cover costs for Sue's salary, travel and materials. Starting July 1, 1976, new contracts were approved for the 1977 fiscal year for $19,483.30 for Home Training and $6,052.80 for respite care. Funding for the purchase of service contracts is from Title XX and state funds (to cover non Title XX eligible families). Administrative costs are extremely low as Sue is the only employee and uses her home for the office, keeps her own books and does her own clerical work. Travel costs are the major expense as Sue travels 4,000 - 5,000 miles per month.

Sue Rose and Hi Line Home Programs, Inc. are beginning to experience a number of problems common to many new programs. First of all, the demand for services is increasing far beyond the available supply. As stated, there is a current waiting list of 20 families. The present caseload is very large for one trainer without considering the necessary travel. Adding the hours spent in travel and actual training, little time is left for program planning, volunteer recruitment, administration, or staff training. Sue is presently working 7 days per week and approximately 12 hours per day. It is doubtful that she

can or should have to continue to carry this load. An additional staff person will have to be recruited and trained. This will necessitate additional office space, increased administrative tasks and higher costs.

Another acute problem familiar to persons working in rural and remote areas is professional isolation. Sue is the only person in Northeastern Montana engaged in home training and respite care. Although her Board and the Regional Council members are extremely helpful and supportive, Sue feels an acute need for ongoing training and continued information exchange. The Developmental Disabilities Training Institute (DDTI) has been of assistance in providing materials and as much consultation as possible but the day to day working climate is isolated and difficult for responsible professionals like Sue. She is now planning a two day workshop with the other home trainers in the state and together they will try to develop a mechanism for ongoing information sharing and professional support.

Conclusions

The Region I Council, the Developmental Disabilities Division, and the Hi-Line Home Program Board are all currently working on developing methods to evaluate the effectiveness of home training and respite care. The evaluation process should include present use, future need, demand for services, measurable increases in the developmental rate of the developmentally disabled client (that can be attributed to home training) and family satisfaction with the program.

A brief assessment of the current program and services provided seems to indicate that home training is a viable and needed service in a rural area. Rural families that have pre-school developmentally disabled children or adult family members at home are often unable to make use of center based programs. The first and most obvious reason is related to time and distance. Secondly, life on farms generally does not allow for one of the adults to leave the farm to transport the family member to a center program on a regular basis. And, thirdly, many rural families are extremely proud and hesitant to seek out services themselves.

The provision of home services is one way to overcome problems of time, distance and resistance. In some ways, it may not be seen as an economical use of a professional person's time but in the case of Hi-Line Home Programs, the fact that Sue spends endless hours driving to distant homes is viewed as very positive by the families served. They feel that for once a real effort is being made to accommodate them rather than the professional person. In such sparsely populated areas, it is very doubtful that out-of-home or center based programs for pre-school children and adults are feasible because of the cost relative to the usage. Itinerate trainers providing services on a regular basis (weekly, monthly) seem to be the only way of reaching many rural families at this time.

However, it should be noted that home training is only one service component needed by rural families with developmentally disabled family members. The problems of diagnosis and evaluation and specialized therapy programs cannot be fully addressed by home training programs. Mechanisms must be developed to make these and other services more accessable. Early intervention through home training is not possible without early diagnosis and referral. Also,

speech and physical therapy programs must be correlated with home training since they frequently play a major role in setting up the actual goals and programs; access to therapy cannot be ignored. Specialized training in simple speech and physical therapy for a home trainer could be helpful in monitoring therapy programs but would not eliminate the need for speech and physical therapy evaluation and ongoing services.

The success of a home training program such as Hi-Line is heavily dependent not only on the training skills of the home trainer but also on the energy and tenacity of the individual. The trainer must possess an understanding of rural families and their cultural patterns as well as a willingness to reside in and be a part of a rural area. The recruitment and maintenance of trainers like Sue Rose necessitates much attention to initial and ongoing staff training as well as exploration of ways to overcome professional isolation.

Small home programs in very rural areas like the Hi-Line appear to be a reasonably cost effective service delivery method. However, as these programs grow due to increased client load, costs for staff, administration, and materials will also increase. Transportation costs may decrease if the size of an area served by one trainer can be decreased. Use of volunteers and well trained Boards of Directors may also be helpful in keeping down program costs.

The Region I Council which serves as an advocate for the developmentally disabled citizens of eastern Montana is proud of Hi-Line Programs, Inc., and plans to continue to support the program. The Montana Legislature is now carefully watching the development of community based services. With full documentation of client progress from Sue, she and the Region I Council will be ready to fully respond to all inquiries from legislators. The future of Home Training and Respite Care for the developmentally disabled seems assured.

CHAPTER 9

SERVICES TO THE DEVELOPMENTALLY DISABLED

A Component of a Model Rural Health System

by

Sally M. Davis

The Checkerboard area of New Mexico presents many of the most challenging factors of rurality, poverty, and cross-cultural problems. The Checkerboard Area Health System meets the challenge of providing health care in this area and operates a model Early Periodic Screening, Diagnosis and Testing (EPSDT) program.

Sally M. Davis, Director of the EPSDT program, describes how the program functions and offers two case studies.

Introduction

Programs designed to assist the developmentally disabled and their families often bypass the rural areas of our country. Problems in rural areas are not as apparent as in the cities and there are fewer spokesmen for bringing attention to them.

Because of the low population density and isolation in rural areas there is difficulty in bringing together children with similar problems for specialized educational, psychological, and medical services. Scarcity of professional manpower in rural areas further limits these services.

Poverty is another problem in rural areas. There is more poverty in rural America, proportionately, than in the cities. According to a report by the President's National Advisory Commission on Rural Poverty, "in metropolitan areas, one person in eight is poor, and in the suburbs the ratio is one in fifteen. But in the rural area, one of every four persons is poor with a total of fourteen million people."[1]

The problems associated with poverty then are probably more common in rural than in urban areas. Problems common to impoverished populations such as infectious disease, environmental hazards, poor nutrition, inadequate health care, and congenital disorders contribute to the prevalence of developmental disabilities. The National Association for Retarded Citizens states in the publication A Plan for Everyone that "A child in a low-income family is fifteen times more likely to be diagnosed as retarded than is a child from a higher income family."[2]

Often the attitude of the indigenous population is not receptive to the service especially when it differs greatly from traditional methods of diagnosing and treating developmental disabilities. The reliance of these traditional methods is reinforced when alternate services are scarce.

A program designed to meet the needs of the developmentally disabled in rural areas must therefore be prepared to address not only rurality but also isolation, poverty, and conflicts in the perception of health care and education.

Background

The obstacles of rurality, isolation, poverty and perception of services are extreme in the Checkerboard Area of New Mexico. New Mexico, the fifth largest state, ranks 49th in per capita income. The population is one million people, one fourth of which live in rural areas of less than 1,000. The Navajo tribe has 140,000 members living in rural New Mexico, Arizona and Utah.

The Checkerboard Area of New Mexico is a remote, arid land of arroyos and mesas juxtaposed with the forest-covered Nacimiento, San Pedro and Jemez mountains. The designation "Checkerboard" refers to the pattern of land ownership by federal and state governments, railroads, Navajo Indians and private parties. The area is tri-cultural with 65% of the population being Navajo, 30% Spanish, and the remainder Anglo and other.

The region is sparsely populated with people living in small villages or scattered hogans. Most of the families are in the low income bracket with 84% of the population being borderline or below the OEO poverty level.

The New Mexico State Planning Office estimates per capita income for Sandoval County, in which much of the Checkerboard is located, at $991 a year. The Indian Health Service estimates average family income for off-reservation Navajos in the area at $1,500 a year or about $300 per person.

The population is spread out over 6,000 square miles which is an average of 2.5 persons per square mile. Buildings are often dilapidated, with water, sewage, and sanitary systems lacking or inadequate. Most water supplies are heavily contaminated with harsh minerals such as magnesium. Many people haul water and store it in barrels and various other containers. Drinking water in the village of Cuba is hauled from a mountain spring. Wood is generally used for both heating and cooking. Ninety percent of the roads are unpaved and often impassable. Telephone service is available to only five percent of the people, and, if present, is undependable. The ethnic and language barriers seriously affect the ability of the residents to secure jobs and to adjust to and benefit from the traditional educational system. Unemployment is extremely high.

The need for medical care in this area was obvious, and in 1971 Presbyterian Medical Services, a nonprofit corporation organized in 1965, received funding from the Social and Rehabilitation Division of the Department of HEW to test the effectiveness of a model health care delivery system in a distressed rural area. The Checkerboard Area was chosen as the site for this project. Further development and refinement of the model has resulted in the continuation of funds from other federal and state sources.

The Checkerboard Area Health System provides outreach, transportation, health maintenance, disease screening, limited outpatient diagnosis and treatment and limited secondary care including emergency and inpatient services at a central health center. Innovative aspects in the System's design include a satellite system of clinics, use of physician extenders, integration of non-clinic components such as public health and an information-flow system of records connecting outpost clinics with the central health center. The satellite clinic system is designed to bring the basic services as close to the people as possible. Six satellite clinics provide almost identical services throughout the area. Each has a waiting area, office and radio room, examining room, laboratory, pharmacy, and medical records area. Most have or will have a dental chair and "set up." All clinics are under the supervision of a certified and licensed nurse practitioner or physician's assistant who has telephone or radio contact at all times with a physician in the Cuba Health Center.

A physician comes to the site once each week to review charts and see difficult cases. Each outpost clinic is staffed with community aides trained to assist in clinic, make home visits, perform simple laboratory procedures, dispense prepackaged drugs and counsel and educate patients. Each clinic has vehicles equipped with mobile radios which are utilized for home visits, staff and patient transportation.

A central health center in Cuba consists of a waiting area, medical clinic, dental clinic, 10 bed inpatient facility including a maternity unit, 24 hour emergency room, central pharmacy, central laboratory, x-ray unit, central radio communications room, central supply room and offices. Each unit is under the supervision of a member of the professional or administrative staff. Each unit has professional or paraprofessional support staff who work under the supervision of the more highly trained or experienced personnel. Two ambulances as well as other vehicles with mobile radio units are based at the Health Center. The System's more sophisticated services are provided only at the central health center. Patients requiring services too sophisticated for the System are usually referred to large medical centers in Albuquerque, Gallup, or Shiprock, New Mexico.

The Program

In 1973 DHEW funded a supplemental grant to develop a rural model for an Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Program. The overall goal was to develop a model for the delivery of medical and developmental screening, diagnosis and treatment services for children which was economically feasible to be replicated in the national EPSDT under Title XIX.

The program began modestly with a staff of five people operating from a trailer behind the Cuba Clinic. The developmental aspect was the primary focus of the program during those early months.

The program developed until the staff numbered sixteen in 1975. A renovated garage and the addition of an old barracks building were made into offices, a large multipurpose room to be used for in-service training, parent training and meetings, and therapeutic classroom, a staff work room, and a storage area. The entire building was converted into comfortable, pleasant work areas with good heating, insulation, lighting and carpeting for a total cost of approximately $10,000.00. The lot has also been landscaped with native trees and rocks by a team of young people attending the vocational component of the program.

The project has been providing integrated medical and developmental screening for the purpose of early identification and follow-up of problems that may affect a child's normal growth and development. Most of the screening has been done in seventeen of the schools in the area. This includes public, mission and Bureau of Indian Affairs schools. The Checkerboard Area Health System, the only medical facilities for six thousand square miles, conducts medical diagnosis and treatment.

The use of the schools for screening has proved effective because children are already assembled and a maximum number of children can be screened at low cost. Reliance upon special transportation, so difficult in this remote region, is minimized.

The screening, as well as case-monitoring follow-up, is conducted by a pediatric nurse practitioner and a psychoeducational diagnostician with a team of specially trained paraprofessional screening personnel representing the Spanish and Navajo cultures indigenous to the area.

The logistical plan includes spacing screening schedules for the area schools over the entire year with three weeks allowed for each school. Initial contact is made with the school and the program is discussed with administrators, teachers and aides. The EPSDT team then conducts medical screening the first week and developmental screening the second week. Feedback by the developmental diagnostician and pediatric nurse practitioner is given to school staff and available parents the third week. The interim days are utilized for case-monitoring, interpretation and scoring, home visits, record keeping, diagnosis and treatment. The plan has been very successful and the three weeks from one medical screening to the next and from one developmental screening to the next allows time for necessary follow-up and prevents lag between identification of a problem and the subsequent diagnosis and treatment. The developmental and medical screenings are conducted only one week apart and feedback given at the same time further integrates these two components. The only carry over from one three week period into the next is the follow-up of children who require more time for diagnosis and/or treatment. Obtaining and recording immunization records sometimes keeps records from being completed at the end of the three week period.

Approximately 2,600 children have been screened; 57.6% of them had confirmed medical abnormalities with an average of 1.24 problems per child. According to available records, only 15% of these findings were previously known and under treatment. Almost all children with positive findings receive diagnosis and treatment. (See Table 1 for areas screened and rates of findings).

Table 1

EPSDT Screening Report, June 1976

Procedures	No. Screened	Percent Positive	No. Positive
Ears	2,220	11.7	260
Eyes	2,221	7.4	166
Nose & Throat	2,218	6.9	154
Skin	2,214	3.4	76
Heart	2,221	7.9	176
Respiratory	2,221	0.4	9
Orthopedic	2,221	0.9	20
Other Physical	2,218	1.6	36
Hematocrit	2,131	1.4	31
Trachoma	2,223	3.8	85
Urinalysis	2,173	4.3	93
T.B.	1,714	0.8	14
Hearing	2,202	8.4	186
Vision	2,214	17.7	392
Other	2,603	0.3	7
Dental	2,292	29.6	678
Total Medical (Excluding Dental)	2,615	45.0	1,176
Total	2,615	57.6	1.507

Children with minor medical problems are treated on-site during the screening. More serious problems are referred to the Health System. The type and seriousness of the problem determines where the child is seen.

Speciality clinics are held on a periodic basis with physician specialists coming from Albuquerque, Gallup and Shiprock. Children with orthopedic, ear or hearing, eye or vision problems, are referred directly to these clinics. Other problems are referred to the physicians and practitioners at the Cuba Health Clinic, or one of the six outpost clinics. Follow-up of patients with ongoing problems is made possible by a register maintained at each satellite clinic and the EPSDT Center. Community aides make home-visits directed by the clinic practitioners, public health nurses, and EPSDT nurses.

Often case-management will require taking a child and his family to Albuquerque or Gallup for further diagnosis or treatment. Occasionally this will involve surgery and a staff member not only takes the family but will stay throughout the ordeal. Often no one in the family can go with the child and he faces surgery alone except for the EPSDT staff member responsible for follow-up. Occasionally the person accompanying the child is allowed to observe the surgery.

Developmental screening is treated as a rough assessment. Labels are avoided and no reference is made to mental retardation, developmental disabilities, or emotional handicaps. Each child is screened in the areas of intellectual functioning, visual-motor perception, emotional adjustment, and English Language facility (language of the schools). Strengths and weaknesses in any of these four areas are identified. Children exhibiting lags in three or four of the four areas screened receive a more complete diagnostic battery. Children with lags in less than four areas are scheduled for periodic re-screening. Children screened more than adequate in any areas are also noted. Feedback is given to teachers on all children screened and enrichment exercises and any follow-up procedures indicated by the screening are explained.

The developmental screening indicates that 14.5% of all children screened needed further diagnostic evaluation. An additional 149 children were referred for evaluation by teachers, parents, and clinic staff.

The program is actively involved with several modalities of therapy for children identified as having some handicapping condition such as mental retardation or cerebral palsy. The multidisciplinary team of professionals in health, education, and psychology and specially trained indigenous paraprofessionals and volunteers have provided counseling, summer enrichment programs, a vocational rehabilitation "tree planting" project, a pre-school program, a remediation component, speech therapy and individual home programs. Professional staff have provided consultations with teachers in the small schools in the outlying region to assist with planning individual programs when special education is nonexistent.

Often the role of the program is to act as facilitator. Families are often unaware where to go or how to go about seeking assistance. The staff helps with contacting outside agencies, enrolling children in special schools, providing transportation, and interpreting for non-English speaking clients. Continuity of services is assured through follow-up. Medical back-up is

available from the staff of the Checkerboard Area Health System and consulting specialists. (See attached Case Studies, Supplement 1 and 2).

Outside services may be paid for by the EPSDT Program, Indian Health Service, private insurance, Medicaid, Crippled Children Services, or other agencies, depending on the eligibility of the child, the service required, the level of funding at that date, and the persistence of the facilitator.

Manpower Training and Utilization

The shortage of trained manpower is a major problem in the delivery of services in a rural area. In an effort to provide services that are relevant and economical, the Checkerboard Area Health System and the EPSDT Program have been concerned with training and employing indigenous personnel.

Training programs are set up as needed and consist of didactic and practical experiences. In-service sessions for both professionals and paraprofessionals are conducted on a periodic basis as a means of expanding and updating knowledge and skills. Staff is encouraged to move up the occupational ladder by seeking additional education outside the local system. At least four indigenous paraprofessionals have completed, or are in the process of training as physician assistants. After didactic classroom instruction a student returns to serve a preceptorship with the medical director in the Checkerboard Area Health System. When training and certification are complete, these people return to serve as physician extenders in the Health System. Scholarships are offered by Presbyterian Medical Services for those who wish to expand their education.

Comprehensive special services for children including medical, psychological, and educational provided from a central location with an emphasis on itinerate distribution is one method of reaching children with developmental disabilities as well as children with other needs when sparse population make pooling of similar disabilities difficult and costly.

The use of indigenous paraprofessionals is an approach that is culture sensitive and economical as well as effective in filling the shortage of trained manpower.

Coordination with a health system provides the medical backup necessary for providing an unfragmented program aimed at the whole child.

Perhaps the most important ingredient in a successful rural program is flexibility. It is necessary to remain flexible and to design and modify policies and procedures so that they are appropriate for the area in terms of ethnic, geographic, social, economic, demographic characteristics. Preconceived plans and rigid procedures predisposes frustration and failure.

Summary

Conditions which may predispose to developmental disabilities are more prevalent in rural America than in the cities. Those who attempt to provide needed services must overcome the barriers posed by rurality, isolation, poverty and conflicts in perception of health care and education. The following six essential ingredients for a successful program should be help-

ful to those who choose to meet the challenge of developing a rural program for the developmentally disabled:

1. Flexibility in developing program policies and procedures.
2. Sensitivity to local language and cultural differences.
3. Mobility to take services to the people rather than try to bring the people to a central location.
4. Comprehensiveness of services to meet various needs of the whole child by multidisciplinary approach.
5. Extension of the professional's time and services by expanding the paraprofessional roles.
6. Coordination with a health system.

The Checkerboard Area EPSDT Program has successfully incorporated these ingredients into a workable model which can be replicated in whole or in part by other rural programs.

Footnotes

1. N.A.R.C. Poverty and Mental Retardation Committee: Plan for Everyone, Arlington, Texas, National Association for Retarded Citizens, 1973, p.6.

2. N.A.R.C. Poverty and Mental Retardation Committee: Ibid., p.6.

Supplement 1 - Case Study

Client: Navajo Female — Connie Simmons, Diagnostician

Education: 2 years, Special Education
(Trainable Multiple-Handicapped Program)

Screening Initiation: This nine year old girl was referred to the EPSDT Program by the health center social worker. A psychoeducational evaluation was requested to help determine appropriate school placement.

Background Information: The client's parents are recently separated. Following the separation, the family moved from a large town to live with the maternal grandfather in an isolated rural area. The family unit presently consists of the client, her three siblings, her mother and grandfather. Her two older brothers are enrolled in the elementary school. Her sister is an infant of less than a year in age.

The mother reported that her child had made a satisfactory adjustment to a special education program in the public schools where she previously lived. She feels that the move to an isolated area with no appropriate school now available is a situation which must be changed as soon as possible. The mother feels that a boarding school would be the preferred placement at this time.

Findings: Medical: The mother states that her child developed normally her first year. She further states that at approximately one year of age, her daughter developed spinal meningitis. Subsequent to this illness, she has had very limited use of her right arm and leg. She is able to walk with the use of a brace. When the client was screened by the EPSDT Program, she needed to be fitted with a new brace as she had physically developed beyond comfortable use of the present orthopedic appliance.

Developmental: A complete diagnostic assessment for psychoeducational development was undertaken by EPSDT staff in February, 1976. Both expressive speech and, to a lesser yet significant extent, language comprehension were severely limited, thereby precluding intellectual assessment involving vocabulary and language skills. Limitations arose in administering and scoring the intellectual performance tests. In some cases, instructions were incomprehensible to the child and for other tasks, the skills required were beyond her capabilities to perform in a manner that could be meaningfully scored.

EPSDT Role: Liaison was maintained with the parent and social worker to facilitate the fitting of a new orthopedic brace as well as finding an appropriate school placement. Particular care was taken to locate a school with an environment suited to this shy, friendly and cooperative client. She had been so positively reinforced by previous school experience that it was deemed of particular importance to place the client in a school which would continue to meet her needs in such a positive way. The client, her mother, the clinic social worker and a Navajo developmental aide from the EPSDT Program explored one special school which had been recommended. Although the school was willing

to enroll the client, it was a consensus that the school would be an inappropriate placement. The school was found to have an enrollment of mostly teenage students, a rather drab physical environment and an appearance of a staff both understaffed and overworked. Further inquiries were made and the child was eventually placed in a boarding school which appeared to be an educational environment which would best meet her special needs. She very happily began her new school early in the summer, 1976. The social worker picked her up at school following a month of school attendance, so that she could spend a brief vacation at home. The social worker's notes indicate that the client is working at her own ability level, and is doing well in adjusting to this new school. It was also noted that the client is well liked by her new peer group.

The case study in this particular instance represents a successful intervention. The educational prognosis for this client appears favorable at the present time. However, it again points out the need for diagnostic services throughout the Checkerboard Area. Without EPSDT intervention, this client would probably still be in need of a developmental evaluation and educational placement. Many clients who are unable, for a variety of reasons, to attend regular schools have been identified and given special educational assistance to meet their special needs during each of the three years that EPSDT has served the area. Without the continuance of the program, such needs can no longer be evaluated and appropriate placements made for the children who are certain to follow in succeeding years.

Supplement 2 - Case Study

Client: Navajo Male

Connie Simmons, Diagnostician

Education (School): None

Screening Initiation: This thirteen year old boy was referred to the EPSDT educational screening and diagnostic section of the Checkerboard Health System as a result of a clinic visit by the family.

Disability: The client attended kindergarten for a very brief period but soon withdrew because of his aggressive behavior toward other children. The stated reason for his not going to school was epileptic seizures on a rather frequent basis. Two years ago he received medical diagnosis and treatment for this condition, and he is now on medication which controls the seizures. He is a middle child in a family of nine. The siblings are all normal and there is no family history of seizures.

Involvement of EPSDT Program: The examiner went to the family camp in an isolated area of the Checkerboard to talk with the family and to make a pre-liminary psychoeducational assessment of the client. The examiner talked with the client's father who indicated that he wanted his son to attend school. The father stated that he was worried because his son, 13 years of age, is unable to understand or speak English and neither reads nor writes. The parents were eager for an evaluation to see if the son might be able to learn. The client appeared very shy but was able to relate to the examiner and Navajo aide.

Certain sections of the Wechsler Intelligence Scale for Children-Revised Edition were administered. Results were not used for making any determination of intelligence other than to get a very cursory overview of how a child, who speaks no English and has never gone to school, is capable of performing. The client appeared to be very eager to cooperate and tried very hard. He seemed to have a desire to go to school and indicated, in Navajo, that he would like to learn to read and write. He identified certain objects with English vocabulary, but only words the family used regularly when there was no Navajo counterpart. It appeared from certain performance subtest results that the client has a degree of intelligence for adequate planning and reasoning. From the informal conversation and communication which the examiner had through the aide, and with the limited Navajo vocabulary which the examiner used in talking with the client, it is felt that he does have a capability of learning. Subsequent to the original report, contacts were made by the EPSDT consulting psychologist with the superintendent of schools. It was the superintendent's opinion that the school had a program which would meet the client's personal needs. The client's family was again contacted by the psychologist and the family eagerly agreed to send the client to school on a trial basis. Arrangements were made for an EPSDT consulting psychologist with the superintendent of schools. It was the superintendent's opinion that the school had a program which would meet the client's personal needs. The client's family was again contacted by the psychologist and the family eagerly agreed to send the client to school on a trial basis. Arrangements were made for an EPSDT staff member, a Navajo developmental aide, to go to the client's home and ride the school bus with him. She spent the day at school with the client in the Language

Enrichment Classroom, and returned by school bus to his home that evening. This support was continued for several days, until the client felt comfortable in his new learning situation. The EPSDT psychoeducational diagnostician observed the client in his classroom following the initial first weeks of adjustment. It was noted that, although extremely shy, he participated in classroom activities with a cooperative attitude. His teacher reported that he had occasional fights with his peer group. She felt the client, who had been so shy at the beginning of his schooling, was making strides in asserting himself in a rather normal "rough and tumble" expression quite typical of his age. He was, she stated, making rapid gains in learning English. The client did not return to school following Christmas holidays. Because of severe winter storms and a high absentee rate due to illness, his absence was not considered unusual. However, with the passing of time, and a realization that the client was absent for an unusually prolonged period, a home visit was made by the EPSDT personnel soon after the classroom teacher expressed concern regarding the client's absence. After a long drive over muddy unpaved roads, no one was home the day the home visit was made. Another home visit was scheduled. This time the aide determined that the child had not wished to return to school because he did not want to be in fights. It was also determined that the client experienced a return of seizures for which he had been treated at a nearby medical clinic with an adjustment in medication. The condition again appeared stabilized. The family expressed a continued desire for the client to be in school but had begun to feel that a boarding school, with a more structured environment, and elimination of a long and tiring bus ride at the beginning and end of each school day, would be best for their child.

Future Plans: The EPSDT staff, together with the clinic social worker, are making every effort to find an appropriate boarding school for the client at the present time. There are several possible placements, but the staff feels it is important to explore further to increase the likelihood of success for the client in his next school placement. It is also felt that it is particularly important for this client to be in a boarding school near enough to his home that he can return for frequent visits and needed encouragement and reassurance.

The story of this child is dramatic, but is not an unusual example of problems representative of the area. Identification of such clients is often slow due to factors of isolation and lack of communication. This client came to EPSDT developmental program attention through a health clinic referral. Following psychoeducational assessment, placement was made within a regular school and initially appeared to be appropriate and successful. However, it now appears that this was not the solution for this child because he was too old when identified for an immediate routine placement to be effective. His problems have grown complex and the answers will require special time and special patience. Alternate possibilities are being explored.

CHAPTER 10

SEEDS OF COMMON SENSE

by

Ted Bergeron

What is rural in some states might be considered metropolitan in others. However, the need to develop programs compatible with the history, economy and culture of the community is applicable to any setting.

In "Seeds of Common Sense" Ted Bergeron, Executive Director of the Shoreline Association for the Retarded and Handicapped, describes a program designed to maximize resources available in semi-rural Connecticut.

Introduction:

In the early years of the sixteen hundreds, the gentle waters of Long Island Sound - having been blessed once by the Totoket and Menunkatuck Tribes - christened the shore with new names, those of Branford and Guilford. North Branford, Madison and Clinton, which complete the list of towns east of New Haven, Connecticut, called the Shoreline, were later sub-divisions of the first two and a section of a large area known as Saybrook.

It is in this setting of rolling hills and hoed-corduroy countryside, linked with stone walls that run down to the sea, that a Puritan people, strong and autonomous, planted the seeds of democracy on the village green. Fortunately, progress in its vision never lost sight of the past, and today these five communities share a cultural bond that preserves their common integrity and sustains their collective values.

It is important to have a sense of history when designing a human service program, primarily because it is history that reveals the value base upon which a community is built. And, it would seem almost common sense that an accurate understanding of a location and how it developed through the philosophy, culture, devotion, economics and politics of a people would be a necessary point of departure in the development of any human service program that is to be an integral part of that location. It is incredible, however, to discover just how often this relationship of people, place and time is ignored. Unfortunately, this has been among the shortcomings of many programs designed for semi-rural and suburban areas.

The Right to Belong

The following is a description of a unique vocational training program, serving fifty adults who happen to have a developmental handicap. It was designed specifically to fit the needs of a suburban/semi-rural area on the coast of southern Connecticut. It is a program so completely in harmony with its community, that it is for the most part in the observations of a vistor that this fact ever becomes verbalized. The sixty-five thousand people who live in approximately sixty-five square miles are invited to participate as a public - not occasionally, but daily - in what might accurately be called a community educational experience. It is an unusual approach, and the fact that it works can be attributed to a little creativity and a lot of common sense.

It is only for purposes of brevity that this description does not include the history of the non-profit, parent organization, Shoreline Association for the Retarded and Handicapped. For it goes without saying that the nineteen years of struggles and successes on the part of its members express for all times their deep belief in the rights of all people; their willingness to take risks; and their healthy virtue of impatience.

Citizenship in a community, taken as a logical construct, implies not only the right to be present, but the right to be included - particularly in all things public. But, it is worthy to note that New Englanders generally guard their privacy, define their property and have a rooted respect for all things earned. The twist in this program design is that it derives its uniqueness from the juxtaposition of values that are both public and private

cast in a setting that is neither totally public nor totally private. And, since it was designed from the onset to serve the general public as well as those who happen to have a developmental handicap, the result has been an interesting and valuable contribution to the concepts of community development.

The community most immediate to the program is Guilford. It is traversed by Route 77, a north/south artery that eventually leads to Hartford, the State Capitol, in about an hour's drive - depending upon one's ability to pass small trucks and tractors on a two-lane highway. Two major interstate Highways, Routes 1 and I-95, run parallel along the coastline on an east/west axis and serve to connect the five Shoreline towns with each other and with the rest of the world - New York being two hours to the west and Boston three hours to the east.

On a knoll overlooking the intersection of these roadways is an inch-for-inch replica of a 1776 Colonial saltbox house so typical of the local architecture. At first glance, it appears to claim this prominent hillside alone, but other roof lines surface upon approaching the back of the curve on Route 77, which guides a visitor to an opening in the stone wall where a sentinel sign bids everyone welcome to "the Apple Doll House Tea Room and Herb Farm." The wonderful aroma of apple-nut cake - the recipe for which is one of life's guarded secrets - drifts down over the meadow and lifts the attention of visitors from the Colonial "hourglass" garden to the Tea Room and Herb Shop above. A hand-scribed menu offers a hungry guest a selection of luncheons that make a decision between an herb-garnished tuna sandwhich on marbleized rye bread or a garden-grown Chef's salad topped with vermillion nasturtiums (an eatable flower) a gourmet's delight. Quiche Lorraine and homemade soups have earned their right to be called favorites. Weight-watchers really should not stay for dessert unless they can resist sauerkraut chocolate cake, hot apple-Betty or pineapple chesse cake! But, the Tea Room really is more than a fine place to eat, and more than a fine facility for the purpose of training three individuals with various handicaps who might be aspiring to a job in food services; it is a place where people meet and often become friends. People, who only a few years ago, might not have had the opportunity to get to know each other . . .

There are many needs met in the intimacy of a thirty-seat tea room, but the instant vacation of slowing down long enough in a fast-moving society is the subtle message whispered by retardation.

About the other roof lines that share the thirteen acres with the Tea Room and Herb Shop: they are part of a grouping of barn-like structures connected to a pair of greenhouses in a way that can only be described as "Yankee ingenuity." The buildings and the land reveal what every artist knows, that beauty and imperfection are one - a theme which belongs to life as well.

People who are drawn to the property by its beauty, may or may not know that they have become part of a training program. What is significant is that they keep coming back. Perhaps it is because the magnetism is in the quality of the experience . . .

Too often the image of Mental Retardation and other developmental handicaps is second-class; maybe it is because too much is accepted that is second hand. Reversing that image in a semi-rural/suburban area requires a commit-

ment to quality, discretion, and diplomacy. But, it can be done.

Approximately one half of the fifty people in training or in sheltered employment are over twenty-one years of age and, for the most part, have completed secondary education. The other half, who are between the ages of sixteen and twenty-one, attend public schools and participate in vocational training on a share-time basis. One delightful optimist in training is over seventy! Without definitions it is difficult to accurately describe functional levels, however, the generally accepted functional levels represented presently in the program range from mild to severe (in instances of multiple handicaps), with moderate classifications best describing the majority of the population served. There is neither a waiting list for training nor is there any anticipation that new enrollment will exceed job placement in the immediate future. Size is an extremely important concept in the development of a program, since it can and does change the total complexion of the service delivered. The philosophy, "small is beautiful", certainly has pervaded the decision process in the design of Shoreline Training and Employment (STEM) Services.

A complete description of the six programs which are provided under the name STEM Services would require a book format. However, the three major areas of training focus upon food services, horticulture, and light industry, since these comprise the most obvious placement opportunities for anyone seeking employment in the Shoreline area. The three major occupational disciplines are sub-divided once again to provide steps of progression based upon the functional and technical ability of those in training. For example, a trainee may spend as many as six to eight weeks preparing meals for fifty people, learning how to operate a semi-commercial kitchen, before being assigned to the Tea Room, where the emphasis is on food delivery and refinement of social amenities.

Horticulture, both on property and out in the community, offers perhaps the most universal training vehicle, in that it can accommodate the highest and lowest functional levels and consistently produce quality results. The miracle of learning takes place whether it is in the simple art of transplanting or in the skill of operating a 14 horsepower tractor.

Industry, once the primary catalyst for vocational training throughout Connecticut, now shares only that proportion which is available to an assembly worker within the Shoreline area. Entry-level training, dexterity and vocational behavior are among the many necessary skills that are taught in a benchwork environment.

Dovetail to the technical training components are the programs for Speech and Manual Language; Slymnastics and Physical Fitness; Hygiene and Sex Discretion; Adult Education and Group Discussion; and a unique program known as Self-Image. Recreation, field trips and leisure time activities are sponsored by the Shoreline Association and/or the local Departments of Recreation.

Perhaps the most unique quality of the program is the fact that it is so diverse for its size - a quality which lends great flexibility to individual programming.

"Creative Financing" offers the best term that could be used to describe the acquisition of the thirteen acre Apple Doll House property and the monies used for the construction of the STEM Services facilities. A Mortgage Participation Loan - borrowed from ten of the twelve banks located within the five Shoreline towns, with one bank serving as originator - provided the necessary capital without having to make a charitable appeal to community resources already committed to operational support. Generous private donations and rent derived from production income combine to make up the monthly mortgage payments.

"The total Operational Budget at present is approximately $200,000 - which includes all administrative support costs. The following is a breakdown by percentages of Income resources:

Title XIX (Medicaid)	35%	Industry	10%
Public School Tuitions	25%	Food Services	2%
Grants		Tea Room and Herb Shop	2%
Department of Mental Retardation	4%	Fund Raising	7%
Division of Vocational Education	2%	United Ways	6%
Health, Education and Welfare	1%	Contributions	6%

Conclusion:

In summary, what is common to the senses establishes the basis for what is known, believed in and trusted. Each community has its own brand of what is common sense, and it is important to identify what that is, because the resources one has are the resources one has . . . and even the best can be improved.

Double-vision in decision making can be corrected by training both paid and unpaid leaders in places away from the community to insure a neutral vantage point. Focus can be improved by democratically setting priorities.

Vision can find new horizons by putting the bifocals of past and future thinking on those who have the responsibility for planning, so that one eye can hold to what is immediate and the other to what is long range; for it is the planner who holds the candle to the darkness.

Listen together to each other first and to the successful believers from elsewhere. If an operation is growing, study the organizations that represent the next stage of development - it avoids pitfalls. Budget for national and international conferences - they are not a luxury - they are a necessity; for they sharpen the senses and serve as a sounding-board.

Lastly, the program that fits the community BELONGS to the community . . . and so do the people who are part of it. Successful innovations are built on "creative conformity." And, needless to say, imitating programs from elsewhere can be a disaster if the personalities of the communities are not similar. It is safer to search for what is noble in the community and to add to that poetry . . .

APPENDICES

Introduction

On Saturday, September 18, 1976, immediately following the conclusion of the Rural Services Workshop, two groups met to discuss special issues directly related to rural issues.

Alice Angney, Chairperson of the Vermont DD Council, and a member of the NCDD Rural Services Committee, led a group on the Concerns of the Minimum Allotment States, those states who receive the minimum federal formula grant funds (currently $150,000) under the Developmental Disabilities Act. A report from that session is in Appendix A.

Thomas E. Scheinost, Staff Director of the South Dakota Developmental Disabilities Council, and also a member of NCDD's Rural Services Committee, chaired the session on Minority Populations in Rural Areas. A report from that session is in Appendix B.

Appendix A

Minimum Allotment States Session:

At the Rural Services Workshop which preceeded the NCDD annual meeting in September, 1976, there was a meeting for representatives of Minimum Allotment States (M.A.S.).

The purpose of the meeting was to provide a forum for M.A.S. representatives to discuss the issues and problems unique to M.A.S. and to explore possible further actions or activities.

Many issues were raised including the following:

- -transportation obstacles in rural/remote areas
- -problems encountered by rural areas when they are expected to implement service delivery models designed in urban settings
- -the erroneous assumption that a unit of service costs the same amount irrespective of the setting in which it is delivered
- -federal legislation and regulations that are not responsive to rural/remote populations.

The participants indicated their support for the formulation of a coalition composed of representatives of M.A.S. by a unanimous voice vote. The purpose of the coalition would be to represent the interests and concerns of the M.A.S. to NCDD.

Subsequent to the M.A.S. meeting, the following resolution was adopted by NCDD.

> Whereas the Minimum Allotment States have common problems directly related to their level of funding, including how Federal legislation and regulation impact the M.A.S., and the high cost of services in many rural states. Be it resolved that NCDD establish a committee to be named Minimum Allotment States for Help (MASH) to form a coalition to address the unique concerns of the M.A.S. and request investigation of possible assistance in this endeavor from DD/TAS. (NCDD adopted resolutions September 21, 1976, p. 2, No. 5)

Appendix B

Minority Populations in Rural Areas

On Saturday, September 18, 1976, an issue session discussing problems and solutions related to service delivery to developmentally disabled minorities in rural areas was held. This session was a part of a three day workshop on Services to Developmentally Disabled Citizens in Rural Areas.

The issue session was designed primarily as a forum for participants to exchange concerns, problems and successful experiences related to serving rural minority developmentally disabled people. Although rural states have numerous minority groups, the Native American population was the group discussed at greatest length.

A resource panel, comprised of individuals with a variety of experiences in programs serving rural minority populations, assisted in generating discussion on the issue. The panel included:

1. Mr. Joe Pearson, Psychologist
   Saint Michaels Association for Special Education
   The Navejo Nation
   Saint Michaels, Arizona

2. Mr. Forrest Snyder
   Area Social Worker
   Division of Social Services
   Bureau of Indian Affairs
   Sacramento California

3. Ms. Patricia Fallbeck
   Department of Special Education
   Black Hills State College
   Spearfish, SD 57783

4. Mr. Ted Taylor
   Deputy Program Director
   Accreditation Council for Facilities for the Mentally Retarded
   Chicago, Illinois

5. Mr. David Touch
   Director of Public Information
   Rehabilitation Services
   Rural Health Services
   RSA-OHD
   Washington, DC

6. Ms. Dorothy Truran
   Services Development Specialist
   Alaska Developmental Disabilities Council
   Fairbanks, Alaska

7. Mr. Lou Wallach
   Assistant Regional Commissioner
   SSI
   Federal Region VIII
   Denver, Colorado

The three day National Workshop on Services for Developmentally Disabled Citizens in Rural Areas was one of the most significant events in the developmental disabilities movement for a number of years. However, the issue session dealing with services to the minority populations within these rural areas may prove to have even more significance. The multitude of unique problems facing rural states in the development of a responsive service delivery system for the developmentally disabled greatly increases when one adds the factor of the minority populations within those rural states. The fact that a national concern for these unique problems is emerging may have very far reaching effects.

Problems being faced by the American Indian and the state Developmental Disabilities Councils responsible for planning for services affecting this minority population group are staggering. In many rural states, various size land areas are set aside as "reservation areas" or as areas under the control of the Federal Department of the Interior, Bureau of Indian Affairs. Many of these areas are not under state jurisdiction, but rather are governed by a tribal council and fall under the jurisdiction of the Federal government. Because of the confused jurisdiction roles, effectively coordinating services and resources available to the Indian people becomes a major task for the state council and the state developmental disabilities agency. Many inadequate and ineffective services are a result of confusion over responsibilities and relationships among various Federal programs and agencies dealing with the Indian people.

The session participants clearly expressed the opinion that the Federal government must begin to recognize the unique problems that exist between state and tribal governments. A suggestion was made that a special planning allotment for developmental disabilities be made available to tribal governments, allowing the Indian people the resources and ability to develop their own developmental disabilities service system. Much of the continued difficulty in developing appropriate developmental disabilities services for the Indian people is a result of the fact that the Federal government, State governments, various professionals, and even private, non-profit agencies (such as church groups) have been playing politics with the lives of the Indian people for many years. More often than not, services have been provided to Indians without finding out if services were appropriate to needs. Many services and programs are often provided that do not take into consideration the unique culture of the American Indian. Many times programs and services are developed in isolation, never taking into consideraiton similar activities being carried out elsewhere. The "reinvention of the wheel" process is very apparent when one views services to the Indian people.

The unique problems of rural states, such as: lack of population, geographic size, lack of transportation, and lack of adequate human services, are magnified on most reservation areas. The issue session brought out the fact that there were some unique and significant attempts to stimulate the development of appropriate services to the developmentally disabled American Indian. The State of South Dakota has, for the past two years, been providing a special planning and program stimulation grant to the Rosebud Reservation in an effort to provide the Indian people with the resources to develop the nucleus for a developmental disabilities service delivery system. One of the primary objectives of this project is to create procedures to allow for the most effective coordination and use of Federal and State resources (both generic and specific) on the Rosebud Reservation. There has also been a substantial increase in programs of the state higher education system with the educational programming on the reservation areas.

The developmental disabilities program on the Navajo Reservation pointed out the massive problems of coordination between three different states and three different Health, Education, and Welfare regions. This program's efforts to carry out an individualized face to face approach in the planning and development of developmental disabilities services has proven to be most successful.

The State of Alaska has placed a great deal of emphasis on the use of the generic service system. The Developmental Disabilities Council serves as a coordinating mechanism but makes very sure that local native Americans are involved in the planning and provision of services. The Council takes great efforts not to impose inappropriate standards and prescriptions for programming on the services being developed by the Alaska Native Americans.

The session participants discussed successful programming techniques emphasizing door-to-door outreach services carried out by the Indian people. An example of use of traditional Indian medicine men as "early identifiers" of developmental disabilities was described. The need for expanded in-service training for Indian people working in developmental disabilities programming, rather than "outside supervision" by so called experts was expressed. Involvement of minority populations in planning and program development efforts at all levels need to be reviewed and expanded in every state.

Summary

The basic objective of this session was to give representatives of the National Conference on Developmental Disabilities the opportunity to focus on the important subject of services to rural minority populations. The session was not designed to formulate any solutions to problems, but rather was designed to bring problems to the attention of the appropriate agencies and organizations. It is this writer's view that the objective was indeed met. As a direct result of the session, the National Conference on Developmental Disabilities passed a resolution which was transferred to the Federal Office of Developmental Disabilities and the National Developmental Disabilities Advisory Council indicating that ... "the National Conference on Developmental Disabilities goes on record as requesting the Federal Office of Developmental Disabilities, Department of Health, Education, and Welfare; and the National Developmental Disabilities Advisory Council to review available developmental disability funding sources, other than State allotments, as a high priority effort to provide planning and service stimulation allotments to Federal Indian reservations or other areas under the control of the Federal Department of Interior, Bureau of Indian Affairs."

The participants in the session also expressed a great desire to have the National Conference on Developmental Disabilities, the National Office of Developmental Disabilities, and the National Developmental Disabilities Advisory Council continue to recognize the unique needs and problems of rural states and the minority populations within those states.